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Goals, information-giving and understanding: a grounded theory study of general practitioners' varied communication about PSA testing

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SCHOLARONE™ Manuscripts Goals, information-giving and understanding: a grounded theory study of general practitioners' varied communication about PSA testing

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Abstract

Objectives:

- 1. To map variation in general practitioners' (GPs') accounts of communicating with men about prostate cancer screening using the PSA test;
- 2. To map GPs' reasons for communicating as they do; and
- 3. To explain why and under what conditions GP communication approaches vary.

Study design and setting: A grounded theory study. We interviewed 69 GPs consulting in primary care practices in Australia (n=40) and the United Kingdom (n=29).

Results: The reported consistency of PSA communication practices in the UK contrasted strongly with the significant variation reported in the Australian context. GPs' explained their communication practices in relation to their primary goals. In Australia three different communication goals were reported: to encourage men to either test, or not test, or alternatively, to support men to make their own decision. As well as having different primary goals, GPs aimed to provide different information (from comprehensive to strongly filtered) and to support men to develop different kinds of understanding, from epidemiological to 'gist' understanding. Taking into account these three dimensions (goals, information, understanding), we derived four overarching approaches to communication: Be screened, Do not be screened, Analyse and choose, and As you wish. We also describe ways in which situational and relational factors influenced GPs' preferred communication approach.

Conclusion: GPs' reported approach to communicating about prostate cancer screening varies according to three dimensions—communication goal, information provision preference, and understanding sought—and in response to specific practice situations. If GP communication about PSA testing is to become more standardised in Australia, it is likely that each of these dimensions will require attention in policy and practice support interventions.

Article summary

- The value of the PSA test as a screening tool for prostate cancer risk is contentious. In many countries, men access this screening via General Practitioners (GPs). Good communication is generally taken to be essential to such screening, to ensure men understand risks and benefits. We analysed how GPs in Australia and the United Kingdom explain their approach to communication with men about prostate cancer screening.
- Particularly in Australia, the communication practices GPs described varied widely.
- Each GP generally preferred one of four approaches, reflecting their communication goals, the information they thought essential to communicate and the understanding they thought men should develop, summarised as: (1) Be screened; (2) Do not be screened; (3) Analyse and let choose; and (4) As you wish. Specific practice situations could lead GPs to diverge from their preferred approach.

Strengths and limitations:

- As this is a qualitative study, we cannot infer prevalence of the four reported approaches.
- Data were derived from a large, rigorously derived sample of GPs from different practice types and locations, and in two countries.

Introduction

- 2 Worldwide, many men undergo regular prostate-specific antigen (PSA) screening for prostate
- 3 cancer risk in primary care. We will use *PSA screening* to refer to PSA testing in ostensibly
- 4 healthy men who are not considered to be at high risk of prostate cancer for their age; this
- 5 contrasts with PSA testing in men who have a diagnosis of prostate cancer or are experiencing
- 6 acute symptoms that may suggest prostate disease. Although the value of the PSA test as a
- 7 screening tool is scientifically contentious, the public perception of prostate screening is
- 8 reportedly positive, including an inflated sense of the benefits and underestimation of the harms
- 9 (1). Access to PSA testing is often via General Practitioners (GPs). The large number of men
- 10 tested, and the extent of public misperception and scientific contention, make the
- communication between men and their GPs about prostate cancer screening especially
- important.
- 13 Communicating about screening is difficult. In-depth discussions about cancer screening can be
- complex, and may involve multiple statistical concepts, such as test sensitivity and specificity,
- 15 and absolute and relative risk reduction figures from trial-based evidence. Chan et al identified
- over 20 specific informational items that experts and patients identified for inclusion in an
- 17 'ideal' discussion about prostate screening (2). The authors synthesised the items into a core set
- of key facts that clinicians should provide about PSA screening to their patients (Figure 1),
- 19 however we note that even some of these items are contentious or inconsistent with the various
- 20 national guidelines that we will discuss in the next section.
- 21 Insert Figure 1 about here
- 22 Proposed communication standards for PSA screening discussions are reportedly challenging to
- 23 implement in clinical practice e.g. (3-5). PSA tests are often ordered in the absence of any
- discussion: US men report being unaware of being tested (6), not being asked for their screening
- 25 preferences, and undergoing PSA testing without first discussing it with their doctor (7).
- 26 Clinicians report offering screening without prior counselling (8). A survey of US physicians

reported 20% acknowledged ordering PSA without telling patients (9), and this can be the case for various reasons (10). Volk et al surveyed US physicians and found that those physicians who reported ordering PSA tests without discussion were more likely to believe that patients wanted testing and that education is not needed. This was in contrast to those physicians who engaged patients in pre-screening discussion because they believed patients should know about the lack of evidence supporting screening (11). Physician beliefs about the limitations of the scientific evidence for PSA screening, the questionable utility of the PSA test, and ethical concerns regarding patient autonomy have also been identified as influencing the likelihood of discussions in US studies (10, 12). Physician beliefs can shape the content of discussions: in a UK study, the strong personal views of clinicians against the value of PSA screening were reportedly clearly portrayed in their presentation of information about prostate cancer screening (13). In addition to this work on physician knowledge, values and attitudes, some researchers have studied patient and practice factors that may facilitate or preclude discussions about prostate cancer screening. For example, in one study US physicians were less likely to discuss screening if a patient had already made a decision about screening, or was perceived to have limited ability to understand the information (10). Other studies have reported on factors affecting the quality of discussions, including a lack of time and the complexity of the topic (9). Clinicians have cited clinical guidelines and scientific evidence about prostate cancer screening as factors guiding their practice e.g. (13). However this professional guidance varies widely, which may partly explain the observed variation in practice. Table 1 outlines the recommendations of key professional organisations in relation to communicating about prostate cancer screening, illustrating the main points of difference. "Informing" men about the benefits and harms of PSA screening is universally recommended; and use of decision support tools is recommended by half of the professional organisations. Only four of the ten guidelines advise whether GPs should raise the topic of PSA screening with men who do not ask about it in routine consultations. Medico-legal issues are referred to in only one, Australian, guideline. In practice,

- clinical guidelines may not always help GPs to decide how and what to communicate about PSA screening (14).
 - Insert Table 1 about here

- Entwistle et al characterised the two main ways that health care organisations communicate with the public about screening *Be screened* and *Analyse and choose* and proposed an alternative approach to communicating about screening, which they termed *Consider an offer* (15). The *Consider an offer* approach suggests health care providers should support people to assess an offer for screening, with a recognition that people may reasonably decline such offers. *Consider an offer* guides clinicians and patients to consider the source of screening recommendations and professional guidance. We return to the *Consider an offer* approach in the Discussion.
 - We draw on a study of clinician's approaches to, and reasoning about, PSA screening in general practice. In this paper we present an analysis of how GPs in Australia and the United Kingdom explain their approach to communication with men about prostate cancer screening. Despite similar levels of prostate cancer mortality, both PSA screening and prostate cancer incidence are lower in the UK than in Australia (16-19). Previous analyses from this study have illuminated systemic variation between the two jurisdictions, including in payment models, the history of PSA screening policy, screening culture, and referral patterns (14). In general, in our data, GPs from the UK had more consistent PSA screening practices than those from Australia. Table 2 summarises our previous findings regarding differences in PSA screening in the two jurisdictions. Note that prostate cancer screening is not recommended in either location.
- 74 Insert Table 2 about here.

- In the light of our prior findings on variation between the Australian and UK contexts, we set out to better understand GP communication practices in particular. We asked the following research questions, in respect of both settings:
 - 1. How do GPs describe their communication with men about prostate cancer screening?
- 80 2. What are the reasons given by GPs for communicating with men as they do?
- 3. Why and under what conditions do GPs communication approaches vary?

82 Methods

Design

- We applied the well-established, systematic qualitative research methodology of grounded
- 85 theory (20).

- 86 Study procedures were approved by the Cancer Institute New South Wales and the University of
- 87 Sydney Human Research Ethics Committee [#15245]. GPs had an opportunity to discuss the
- 88 study with KP prior to participation; all GPs provided informed written consent to participate.

Participants and Setting

- 90 We recruited a sample of 69 GPs (40 Australian, 29 from England, Scotland, and Wales). See
- 91 Pickles et al (21) for a detailed description of the recruitment process. GPs were invited to
- 92 contact KP if they were interested and willing to participate. Participants were of varying ages,
- 93 clinical experience, gender, and patient populations: all GPs who expressed interest in
- participating were included. GPs were compensated for their time.

Interviews / Data collection

- 96 We generated data via in-depth interviews. The semi-structured interview schedule covered a
- 97 broad range of topics, including GPs' recent clinical encounters involving PSA screening
- decisions, communicating information about the PSA test to patients; screening pathways; and
- 99 overdiagnosis of prostate cancer. Example questions asked about communication included:

- Describe a recent consultation involving the PSA test...Can you take me right back to the
 beginning and tell me as much as you can about the consultation. Who initiated the
 conversation about PSA?
 - Should men be informed about overdiagnosis, false positives before having a PSA test?
 - How well do you think men understand PSA screening?

The schedule was modified between interviews based on the developing analysis to enrich the data available to answer our research questions. All GPs were asked to think back to their most recent consultation involving a discussion about PSA screening or to describe a typical consultation where the topic was raised.

Interviews took place between March 2013 and June 2014 (Australian GPs) and between September and December 2014 (UK GPs). All interviews were conducted by KP, primarily by telephone or Skype, and ranged in duration from 18 to 70 minutes. All interviews were audio-recorded, and were transcribed verbatim.

This study started in Australia, where we found significant variation in GPs' reasoning about and use of the PSA test. There are some important differences in the organisation and funding of primary health care between Australia and the UK, including in the advice offered to GPs about prostate screening. We extended our sampling to the United Kingdom to explore the role of context in PSA screening approaches, explanations, and patterns.

Data coding and analysis

The analysis was led by KP, who coded the transcripts and wrote detailed memos which were reviewed and discussed by the authors in analysis meetings. A subset of transcripts was read and coded by three authors independently; this coding was compared and discussed to inform the development of the central concepts in the study.

Results

We observed considerable diversity in the ways that GPs' described their communication about prostate cancer screening. This was particularly observed in the Australian context, possibly

and different.

because the Australian health care system provides less consistent and directive guidance to GPs about how to communicate with men on this topic, alongside differences between Australia and the UK in social, historical, and structural factors as identified in our previous work (14). Although the majority of variation occurred among Australian GPs, we also report on data from the UK because this helps illuminate the contrasting complexity of the Australian data, including the role of local context.

We first explain how Australian GPs' varied in their descriptions of their communication style. In the second section, we consider important ways in which UK and Australian GPs were similar

How Australian GPs communicate with men about prostate cancer screening

Australian GPs' accounts varied greatly in how they introduced conversations about PSA screening with men, how screening discussions were framed, and their perceived informational obligations.

Some Australian GPs screened men for prostate cancer with little or no prior communication

A minority subset of interviewees reported ordering PSA tests with little or no prior communication with the patient. Several possible justifications were provided. Some said their role was to ensure that men could be tested if they wanted, 'I see doctors purely as enablers, of what people want...If you don't want to read about it [the test], then fine; I'll just order one for you' (AGP17). Some considered it unnecessary to provide information unless the man received a cancer diagnosis, 'I don't think they need all that information at the level of PSA testing. I think, that once you've got your cancer diagnosis, you can talk about what you want to do with that then' (AGP26). Some reasoned that because the information about PSA screening was 'confusing' 'complicated' and potentially contradictory, it should not be provided. There were a number of GPs who did not appear to have a complete understanding of the epidemiological data, for example, 'someone was saying that a certain number of people had to have radiation and surgery

and have impotence and incontinence, for one person's life to be saved. I mean – I don't know how you get those figures' (AGP2).

A small minority considered it 'up to each patient to be informed appropriately' (AGP14); if a man requested a PSA they would order a test assuming that man felt sufficiently informed from other sources. We encountered occasional practices from which men were mailed pathology forms for a PSA test via practice recall systems, bypassing a GP consultation and opportunity for discussion.

These were, however, minority views. We focus in what follows on the majority of GPs who *did* communicate with men in some way about PSA screening.

When communicating about prostate cancer screening, Australian GPs varied on three key dimensions

We identified three dimensions central to GP discussions with men about PSA screening:

- The GPs' primary communication goal. Some GPs had the goal of convincing the patient
 to screen, some had the goal of convincing the patient not to screen, and some had the
 goal of supporting decisions or facilitating patient choice;
- 2. The type of information the GP provided; and
- 3. The type of patient understanding the GP sought to achieve.

172 It appeared that Dimension 1 was dominant: GPs communicated in accordance with their
173 preferred goal or outcome of the communication. In most cases, the GP's positioning on
174 dimensions 2 and 3 was grounded in whether the GP felt strongly that patients should be
175 screened or not, and the degree to which they directed men towards that preference. Below we
176 explain these three dimensions, and GPs' reasoning about them.

Dimension 1. GP's primary communication goal.

GPs reported different goals for the communication process: respectively, to encourage men to either test, or not test, or alternatively, to support men to make their own decision. Some GPs aimed to convince men either to agree to be screened, or to agree not to be screened. These GPs had

strong beliefs regarding whether or not PSA screening should occur routinely, and wanted patients to follow their advice: their 'guide...down the path' towards what they 'thought was best' (AGP29). GPs acknowledged 'bias will creep into that' (AGP29): 'you can't help yourself but...what you believe in is the way you push the consultation' (AGP18). However this approach was justified by beliefs that, '...you can only do what you think is best for the patient' (AGP29) and 'a lot of people do want to be told what to do...doctors are their reference point' (AGP31). GPs recognised that men sometimes chose not to take the advised pathway, for example, 'there are times when it wouldn't matter what you said to a patient they're still determined to have the test' (AGP18).

An alternative GP communication goal was to support men to make decisions consistent with their own values and preferences. GPs with this goal aimed to facilitate an informed decision making process and were determined to provide information to all men 'to make up their own mind' (AGP16), because 'patients want to be given the knowledge and the understanding so that they can make a decision themselves' (AGP5). GPs with this goal reasoned that a man 'should have the right and want to be able to make that decision for themselves about whether they have the test or not' (AGP5).

Dimension 2. GPs provided different types of information.

Because GPs had different goals in communicating, they provided different information, in both quality and quantity.

Some GPs claimed to provide men with 'complete' and 'unbiased' information because they

considered it their 'ethical obligation' as a health professional to do so: the patient, in this view, had a 'right' to be fully informed, so GPs should '[put] all the information on the table' (AGP31). This sometimes extended to teaching patients how to locate and interpret information for themselves. Fully informing patients was described by some GPs as serving a self-protective legal purpose, 'I've informed the patient, the patient made his own decision, so he's got to then accept the consequences' (AGP19).

In contrast to GPs who sought to provide comprehensive information, other GPs filtered information to 'actually tell them [patients] what counts the most' (AGP4). Here GPs aimed to

explain their own best judgment about the evidence, framing the evidence according to the GP's opinion regarding the value of PSA screening. This often took the shape of a personal recommendation either to have a PSA test or not. One GP, for example, said '[patients] don't have that knowledge so you sort of, give an explanation why it needs to be done' (AGP35); another, in contrast, thought 'my discussing it has probably been biased towards not getting it done' (AGP16). Some GPs considered such advising to be best practice, because information provision alone was not enough to help men decide what to do. For example, one GP who favoured PSA screening reasoned: 'If they really don't know what to do then [after receiving information], any doctor would be a fool not to say look, get it investigated because, the most stupid thing anyone could do is say oh don't bother about it...that's just a total recipe for disaster' (AGP31).

Dimension 3. GPs aimed for men to gain different types of understanding.

All GPs aimed to support the development of patient understanding. However there were two different conceptions of what constituted appropriate understanding of the information presented and available options:

1) Sometimes GPs aimed to assist men to develop detailed *epidemiological understanding* of the evidence. They wanted men to understand all aspects of the information provided and described checking understanding, identifying gaps in patient knowledge, and clarifying misunderstandings. Some of these GPs reported feeling personally and professionally responsible for presenting the 'right amount' and 'right level' of information for individual patients, '[achieving understanding is] really the doctor's job, and our skill in trying to explain all that complicated evidence, as best as we can' (AGP19). Some GPs commented they hoped men understood the detail of the evidence, otherwise it indicated they as a GP had done a 'bad job of explaining it' (AGP6).

2) Alternatively, GPs might aim for men to develop overall 'gist' understanding. GPs committed to 'gist' understanding were satisfied if their patient had a less complete grasp on the intricacies of the evidence base, as long as they had an overall understanding of what the GP perceived to be core issues; 'I feel like as long as they can understand that basic concept [in this instance, that

PSA is not a perfect test] ...then I feel like it's okay to still do the testing, even if they don't understand all the detail...I feel like that's a reasonable level of understanding, I don't feel like people need to have an absolutely thorough kind of understanding' (AGP5). Those GPs who thought 'gist' understanding was acceptable thought it was reasonable for men to trust their doctor to advise them appropriately.

Relationship between the dimensions

When taking account of the three dimensions along which GPs varied, we identified four overarching approaches to communication: (1 & 2): Be Screened and Do not be screened (GPs who guided men towards screening or not screening); (3) Analyse and choose (GPs who aimed to ensure men made their own independent, informed decision); (4) As you wish (GPs who simply facilitated the man's stated preference to be tested or not tested). Two of these terms (Be Screened and Analyse and choose) align with Entwistle et al's characterization of communication approaches (15), as outlined in the introduction. Each GP we interviewed had a general preference to employ one of these four approaches in their everyday communication about PSA screening. In Table 3 we present an integrated illustration of the characteristics of each approach, ordered according to the 3 key dimensions evident in the GP accounts.

Insert Table 3 about here.

Be Screened or Do not be screened interactions. If GPs had a strong preference that men should either be screened or avoid screening, they communicated in a directive way, oriented to encouraging the man either to screen or avoid screening respectively. This included offering personal judgment about the value – or harms – of PSA screening or framing the information they provided towards or away from screening. Some GPs gave a recommendation without offering men any further information. In Be screened and Do not be screened interactions, GPs considered it sufficient that men developed gist understanding of the information provided, because they thought it was reasonable for men to trust their doctor to advise them appropriately. These GPs strongly believed either that men should be screened routinely, or that they should not be screened at all, and they wanted patients to follow their advice.

Analyse and choose interactions. If GPs aimed to support men to make their own decisions, consistent with the man's personal preferences (i.e. a patient-directed decision), then they were not directive in their communication. In these interactions, GPs aimed to provide a comprehensive and impartial summary of the best available evidence; their goal was to ensure that men developed a detailed epidemiological understanding of their options in order to make an informed decision. They saw this as a neutral, educative role. For some, this approach was protective against potential medico-legal threats. GPs using this approach may personally favour either screening or not screening, but their primary commitment was to support the man's decision, regardless of their own beliefs about screening.

As you wish interactions. Sometimes GPs acted on patient wishes to be screened or not screened without questioning. In these interactions GPs did not attempt to direct men in any particular direction, and often provided little information: ensuring that the man understood PSA

direction, and often provided little information: ensuring that the man understood PSA screening was not a priority. In some cases, GPs perceived men to have already made a screening choice based on personal preference or gist understanding. These consultations typically involved men with an already-established screening preference – mostly for screening: the GP simply acted in line with the man's instructions.

How GPs negotiate communicating within specific contexts

GPs positioning on the four approaches seemed relatively stable; GPs tended to have a preferred approach for most PSA interactions (to guide patient toward screening or not screening, to support men to make their own decision, or to act in accordance with the man's expressed preference). However we identified ten situational and relational factors (see Table 4) that GPs described as temporarily shifting their usual or preferred communication goals and processes. These factors predominantly arose from specific circumstances of individual consultations. GPs described 'leaning towards the art of medicine rather than the science' (AGP40), with the aim of providing more or less information or advice (i.e. modifying directive role), depending on the ten factors described in Table 4.

Insert Table 4 about here

GPs also shifted between the four communication options more readily when they were presented with complex cases; producing more fluid, responsive, and sometimes 'quite inconsistent' (AGP16) approaches to communication. Many GPs did have a primary goal when communicating (to encourage or discourage screening, or to support the man to make his own decisions) but these could change in different situations. Also, some men did not take the advised pathway – either toward screening or not screening, or some men preferred the GP to direct the decision, not wanting to engage with information or to make their own decision.

Comparison of communication approaches in Australia and the UK

As highlighted in the findings of our previous work (14), GPs in Australia and the UK have different starting points for conversations about prostate cancer screening. UK GPs generally did not communicate about PSA screening unless men asked about it - so they often neither communicated about it as a screening test, nor ordered it. When men asked for a PSA test, information provision was central to consultations, and most UK GPs commonly practiced according to the *Analyse and choose* or *Do not be screened* approaches. Few UK GPs described adjusting their conversations about PSA screening with patients.

The reported consistency of PSA communication practices in the UK contrasted strongly with the significant variation reported in the Australian context (Tables 3 and 4). The contextual factors considered in Table 4 were uncommon in UK GP's accounts, due to fewer men requesting and fewer GPs suggesting prostate screening. Many Australian GPs reported discussing PSA screening with men often, so had a prepared basic 'spiel': as one reported, 'the PSA is such a common question that you get asked and you just have to have some idea in your head what you're going to say when they come in' (AGP18). This spiel could be tailored to specific contexts as necessary. In contrast, UK GPs mostly reported giving the same standard information leaflet to all men who expressed interest in PSA screening, regardless of their personal circumstances. Many GPs practicing in Australia tended to filter information, and commonly practiced according to the Be Screened approach, but no UK GPs reported using this approach.

We identified different versions of the *Do not be screened* approach adopted by Australian and UK GPs. For the Australian GPs, this approach took the form of a personal recommendation against screening, directed by the GP and according to their personal – negative – perspective of PSA screening. For UK GPs, the *Do not be screened* approach also involved the GP recommending that the man should not be screened. However UK GPs explained this as enactment of a collective standard of care recommended and issued by the UK National Health Service irrespective of their own personal preferences for or against screening.

Discussion

This analysis suggests that GP's primary communication goals are a central component of consultations about prostate screening. Australian GPs had different goals: to encourage men to either test, or not test, or alternatively, to support men to make their own decision. There were two other ways in which GPs reported communication practices varied: the information they provided, from comprehensive to strongly filtered; and the understanding they wanted men to develop, from epidemiological to 'gist' understanding. These latter two dimensions seemed strongly guided by the GP's communicative goal.

Four distinct communication approaches – *Be Screened, Do not be screened, Analyse and choose,* and *As you wish* – were identifiable from GPs' accounts of their preferred practice. Each approach integrated specific elements of the 3 dimensions, stemming from the GPs' goals, and entailed a clear recommendation towards a particular outcome (*Be Screened* and *Do not be screened*), more or less information and support to make an individual decision based on the available options (*Analyse and Choose*), or simply acting in accordance with a patient's preferences (*As you wish*).

The terms *Be Screened* and *Analyse and Choose* align with Entwistle et al's Consider an Offer framework. We identified two additional ways of communicating unique to our empirical data, which we labeled *Do Not Be Screened*, and *As you wish*. The need for inclusion of a *Do not be Screened* element is likely a product of the Australian context where the PSA test is available and widely promoted for screening purposes in the media, despite the majority of relevant public

health and health professional groups recommending against it. This meant Australian GPs were regularly consulted by men expecting to receive a PSA test, and some reported feeling obligated to actively direct men away from PSA screening.

The *As you wish* category is also likely to be, in part, a reflection of the somewhat market-driven Australian health care system, as reported previously (14). *As you wish* interactions occurred when GPs believed men had already made up their minds about their preferred choice, and could not be swayed by information presented by the GP. This led GPs to implement the man's choice and order the test, despite the lack of an evidence base to support that decision. There was no evidence of *As you wish* interactions in the UK data. As we previously reported, in the UK there is strong guidance to GPs to practice in a particular way. GPs are expected to steward limited NHS resources, and the PSA test is not publicly promoted to the same extent, limiting consumer expectations for testing. All of these are conceivable explanations for why *As you wish* interactions were less commonly reported in UK interviews.

The main issues raised by this analysis

The four variants raise important questions about patient-centered care, consumer demand, and the role of the health professional. It is well established in the literature that both patients and clinicians are rarely entirely rational, and may not necessarily know what is in the patient's best interest, particularly when faced with scientific uncertainty e.g. (22, 23). Humans tend, for example, to become sensitized to worst-case scenarios and disregard objective risk probabilities; this makes us vulnerable to pursuing, recommending, or accepting potentially harmful treatments (24). If this is so, an *As you wish* approach could mean patients are more exposed to increased harms, and that leaving patients to make decisions about their health care needs without professional guidance is potentially maleficent, or at least negligent. This problem is further complicated by the wide availability of potentially misleading information, provided by sources that have an interest in inflating risk perceptions. Some authors highlight that increased patient involvement in decision making has potential for negative social consequences such as increasing patient demand for unproven services (25). Cribb and Entwistle reasonably

argue that in some circumstances it may be ethically legitimate for health professionals to question and even influence the preferences of patients for these reasons (26). Most current recommendations encourage GPs to discuss the benefits and harms of prostate cancer screening with patients. However, there may be considerable variation in what patients want and expect from GPs prior to making a decision about PSA screening. Degeling et al ran three community juries on the topic of how GPs should communicate about PSA testing. Juries heard extensive expert evidence about PSA screening, consent and general practice. Two juries of general citizens (i.e. mixed gender and age) concluded GPs should ensure men have enough knowledge to make their own decision. One jury of only men of PSA screening age concluded that men should be able to trust their GP (or a specialist) to provide just enough information at just the right time, expressed concern about the potential for information overload, and thought the degree of patient involvement depended on the patient (27). This suggests that citizens who are (atypically) well-informed about the benefits and harms of prostate cancer screening may take different views and have different expectations on how GPs should communicate about PSA testing. If this is the case, it may be appropriate for GPs to have at least a range of communication strategies available, to suit the needs of different patients. Men eligible for, or already receiving, PSA screening, may well prefer for GPs to direct the decision (Be screened or Do not be screened approaches) to avoid uncertainty. However men's preferences are arguably an insufficient guide: other considerations, including clinical practice guidelines, medical law and clinical ethics requirements, are relevant to determining what GPs should do. A large component of this analysis is about awareness of and sensitivity to context and the importance of interpersonal relations and their influence on communication practice (see Table 4). Some of the GPs' communication decisions, based on situational or individual factors, were easily justified, because the situation presented was either clinically relevant (e.g. family history, older age), or professionally justified (e.g. low literate patient, patient request). While most guidelines advising on PSA screening suggest informed or shared decision making, they do not consider what may be a 'best' approach to situations involving the many local factors GPs face in

day to day practice, including relational factors, implicated in screening decisions (and the complexities of general practice). We identified a subtle web of relational issues that influenced GPs to move between communication options and particular types of decision pathways. These included managing colleague associations (what are GPs to do about patients who have come from a pro-screening GP to a GP who does not support PSA screening?), managing business, including patient lists (patient request, time pressures), and maintaining patient trust. These issues made the decision making process particularly complicated, and in addition to vague guidance on such matters, perhaps account for why many GPs appeared to have multiple, dynamic approaches. Accounting for relational variables as identified in this study can facilitate nuanced assessment of the different types of support clinicians might offer people who may struggle with particular decisions (28), and allows scope for professional expertise; the 'art' of medicine.

Implications for policy and practice

There are variable approaches to communication about PSA screening, some of which may be considered 'better' than others. Guidance about communication - not just about the PSA test itself, but also about how best to facilitate the decision – may be useful; we suggest there is a need for further higher level professional discussions about what the primary goals of GPs should be when communicating about PSA screening. Coming to an explicit agreement on what that purpose should be may assist in improving communication and providing clearer guidance for GPs working in the Australian context.

Conclusion

This empirical study produced evidence documenting varied approaches to communication. In the Australian setting, multiple methods of communicating (including GP or patient-led) may be justified as a good approach. Further, because of (a) the large number of men implicated, (b) the known harms of the screening process, and (c) that PSA is not a routine screening program, we argue that PSA screening is a particularly pressing case to necessitate dedicated effort to facilitate particular conversations that include but go beyond potential harms and benefits with

men. This would include encouraging and enabling men who ask for screening to look carefully at why PSA screening is not recommended (to increase awareness of why a *Do not be screened* approach is justified). This may necessitate dedicated training for GPs to assist with the additional work that will be required to facilitate these conversations with patients, but should offer the added advantage of supporting men's autonomy and reducing harm.



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Figure 1. Proposed content for informed consent for PSA screening (Chan et al., 1998)

Basic minimum

- 1. False positive PSA test results can occur.
- 2. False negative PSA test results and false negative biopsies of the prostate can occur.
- 3. Nobody knows whether regular PSA screening will reduce the number of deaths from prostate cancer.

Conversation

- 1. The PSA test is a blood test for prostate cancer.
- 2. Done together, the digital rectal examination and the PSA test can screen for prostate cancer.
- 3. The PSA screening test can detect prostate cancer sooner than the digital rectal examination alone.
- 4. An elevated PSA test result may lead to other tests to see whether prostate cancer is present.
- 5. The risk of getting prostate cancer is higher in a man who is older, has a family history of prostate cancer, or is African American.
- 6. Prostate cancer may grow slowly and not cause any symptoms. That is why prostate cancer may not kill older men. They may outlive this cancer and die from something else.
- 7. A man over age 70 is less likely to die from prostate cancer even though he is at higher risk to have it.

Brochure

- 1. The PSA screening test is controversial.
- 2. There are advantages and disadvantages to taking the PSA test. One disadvantage is that a man could end up worrying about what an elevated PSA test result means.
- Done together, the PSA and DRE are most appropriate for men who have more than 10 years left to live.
- 4. A man with early prostate cancer can choose watchful waiting, radical prostatectomy, or radiation therapy.
- 5. There are side effects from prostate cancer treatment such as impotence, incontinence, narrowing of the urethra (strictures), trouble urinating, and rectal scarring.
- Nobody knows whether treating prostate cancer early is helpful or whether one treatment is better than another.
- 7. Although a man thinking about taking the PSA test can consult a doctor, he should make the final decision himself.



Table 1. The recommendations of professional organisations in terms of communicating about prostate screening

d in recommendation and	Professional Organisation									
guidance 6	PCFA/CCA ¹	NHMRC ²	RACGP ³	USANZ ⁴	NICE ⁵	NHS/PHE6	USPSTF7	ACS8	NCI ⁹	Al
oo v t whether to raise the if & en do not raise it first?			1		1	1	1			
9 recommended?	1	✓	1		1					
11 lpmpvided?						✓				
13 nen1dded? 15	1	1	1	1	✓	1	1	✓	1	
ne1.6ed? 17			1		1		✓			
om (& nied by a clinician et ? 9	1	/				1	1			
om20anied by a patient et24		1	1		1	1				
recommend clinician to share creching decision?							1			
24 o- 25 al responsibilities?			1							

tato Gancer Foundation of Australia/Cancer Council Australia

nl Health and Medical Research Council Istralian College of General Practitioners

cal **39**ciety of Australia and New Zealand

nal**36**stitute for Health and Care Excellence

⁶ NHS/PHE: National Health Service/Public Health England

⁷ USPSTF: United States Preventive Services Task Force

⁸ ACS: American Cancer Society

⁹ NCI: National Cancer Institute of the National Institutes of Health

¹⁰ AUA: American Urological Association

be 3 on Making (IDM): The patient is presented with all the information pertinent to making a decision and then assumes final authority for the decision (29). isi🕯 Making (SDM): The patient is provided with all the relevant information and works with the health care provider to reach a decision that reflects the healt of33e patient (29).

information sheet is a fact sheet summarizing the evidence of benefits, limitations, and associated risks of prostate screening to help clinicians to accurately info

nformation sheet is a fact sheet outlining the benefits, limitations, and associated risks of having a PSA test for prostate cancer risk.

Table 2. The organisation and occurrence of PSA screening in Australia and the United Kingdom [summary of findings, details reported in Pickles et al 2016]

 PSA screening is available. GPs are advised to offer evidence-based decisional support to men considering whether or not to 	PSA screening is available, but with conditions. The National Health Service Prostate Cancer Risk Management
have a PSA test, including the opportunity to discuss the benefits and harms of PSA screening before making the decision.	Programme (PCRMP) has recommended that screening for prostate cancer be available for asymptomatic men, on the understanding that they have been provided with full and balanced information about the advantages and limitations of the PSA test.
 GPs reported frequently providing PSA screening within routine consultations. GPs reported often initiating discussion of PSA screening; GPs reported commonly receiving requests for PSA screening. 	 GPs reported that PSA screening was rare in practice. UK GPs reported not promoting PSA screening; they also reported that men rarely asked for PSA screening.
 GPs are free to practice according to individual standards. Australian guidance was mixed (see Table 1). The NHMRC has recently issued guidance to Australian GPs to drive greater consistency in practice. 	Government-issued standards for PSA screening and communication processes in clinical settings are in place. Guidance has been distributed to all GPs in England and Wales to assist in the provision of information to men. GPs can choose to follow issued guidance but seem inclined to operate within the bounds of their health system.
GPs reported generally informing men via a verbal discussion of PSA screening.	GPs reported relying on a standardized printed information leaflet. This was central to the consultation, sometimes alongside a brief verbal discussion.
PSA screening tests were usually discussed and ordered in a single appointment.	Information-giving occurred in a separate appointment to PSA screening itself.
	 GPs reported frequently providing PSA screening within routine consultations. GPs reported often initiating discussion of PSA screening; GPs reported commonly receiving requests for PSA screening. GPs are free to practice according to individual standards. Australian guidance was mixed (see Table 1). The NHMRC has recently issued guidance to Australian GPs to drive greater consistency in practice. GPs reported generally informing men via a verbal discussion of PSA screening. PSA screening tests were usually discussed and ordered in a single

Table 3. Four GP approaches to communication about PSA screening in clinical interactions

BE SCREENED interactions

What is the GP's main goal?

- GP strongly believed that the man should be screened
- GP goal is to convince the man to screen

What information was provided?

- GP's personal judgment about the value of PSA screening
- GP either tailored information provided to men to encourage men to be screened, or did not provide information (provided only encouragement to be

What type of understanding was considered adequate?

Gist understanding of any information provided

ANALYSE & CHOOSE interactions

What is the GP's main goal?

- GP may personally support testing or not testing
- Despite their personal beliefs about testing, GP's goal is to facilitate the patient to make his own informed decision

What information was provided?

GP aimed to provide a comprehensive and impartial summary of best available evidence

What type of understanding was considered adequate?

GP goal was to ensure men developed detailed understanding of their options, to make own informed decision

DO NOT BE SCREENED interactions

What is the GP's main goal?

- GP strongly believed that the man should not be screened
- GP goal is to convince the man not to screen

What information was provided?

- GP's personal judgment about the harms/downsides of PSA screening
- GP either tailored information provided to men to discourage screening, or did not provide information (provided only encouragement to avoid testing)

What type of understanding was considered adequate?

Gist understanding of any information provided

AS YOU WISH interactions

What is the GP's main goal?

- GP may or may not have a strong position on the value of PSA screening
- GP's goal is simply to follow man's expressed preference

What information was provided?

GP provided little information

What type of understanding was considered adequate?

Ensuring the man understood was not a priority for the GP. In some cases, GP perceived men to have already made a screening choice based on personal preference or gist understanding

Table 4. The effect of practice situations on GPs' approaches to communication in PSA screening interactions, as described by GPs

3	
that encouraged particular approaches munication about PSA screening, as 6 described by GPs	Examples of how GPs reported modifying their communication
is from an older or younger age group rlyounder 50 years or over 75 years), or bidities 11 12 13 14	 Some GPs paid closer attention to which direction they 'coaxed' patients in these age groups; for example, some would particularly emphasise false positives and the potentially harmful diagnostic pathway to younger men under 50 years (i.e. GP more likely to use Do not be screened approach). Some GPs who usually communicated in Be Screened mode provided comparatively less detailed information for older patients, particularly those with declining memory or those they perceived as being cognitively unable to 'handle the information', and 'pick[ing] the details of the intricaciesand a lot briefer [conversation]' (AGP17)
16	Some GPs described defaulting to providing stronger recommendations with elderly men.
juckgement that the patient 'starting erms of grasping the information was we gld be difficult for them to d BSA screening 21 22 23 24	 Some GPs who usually favoured Analyse and choose, reverted to a Be Screened or Do not be screened approach when communicating was difficult, 'If I had a patient who is extremely unintelligent and I tried to explain it and I didn't seem to be getting through to him, and I felt it was in his best interests, I might go ahead and do the test [or not do the test] anyway' (AGP29) Some GPs tailored the content accordingly; 'it really depends on the population you're dealing with what you perceive they are capable of understanding' (AGP31); 'You've got to target it at the level of the patient basically' (AGP4).
25	• 'If a man thinks PSA is just a blood test, then I mentally go oh dear, we need to go through
26	this in more detail' (AGP4).
tion with limited access to urology 28 29 30 31 32 33 34 35 36 37 38 39 40 41	 Some GPs were influenced by their access to a Urologist. Although they might prefer to recommend that men <i>Be Screened</i> or <i>Do not be screened</i>, they described instead shifting their approach towards <i>Analyse and choose</i> when based in a rural location; I <i>'just might try to explain the test, do a bit more pre-test counselling with the patient when I was in the country, just because I knew that I'd then be managing the result rather than just sending them onto a Urologist, like it's easy to do in Sydney' (AGP5). GPs described how in rural locations it is common for GPs to have to manage abnormal PSAs for a longer period before they can access urologists for a second opinion. Some GPs were uncomfortable with this situation and consequently aimed to involve men more in the decision from the beginning.</i> Some GPs would talk to patients after PSA screening if it was abnormal but not before; i.e. they would take either a <i>Be Screened</i> or <i>As you wish</i> approach before testing, and provide counselling if needed after testing. These GPs perceived some men as resistant to seeing a GP at all, so thought it important to be seen to do a test because it was 'something' proactive for them while they were there, rather than simply talking.
ald? for the consultation (GP short of	Some GPs who preferred an <i>Analyse and choose</i> approach engaged in less detailed
43	20.110 d. 2 milo preferred diffinal/200 diffa encode approach engaged in 1635 detailed
44	

1	
2 3 4 5 6 7 8	discussion with patients about PSA screening when they were short of time. They described selecting out the information to include in discussions with men when they were time poor, more in line with the <i>Be Screened</i> or <i>Do not be screened</i> approaches. Some GPs said it is often simply impractical to provide full information and support patients to develop detailed epidemiological understanding at each appointment so on occasions they 'just haven't had time to give a full spiel so I order it and I will have the discussion later with them, if it's positive' (AGP13).
is Perceived to be anxious, and so not to information 11 12 13 14 15 16	Sometimes GPs provided minimal information to manage anticipated patient anxiety; 'if you put too much information out theremost of it doesn't go inthere's too much information'it's not possible for people to take that stuff in, they don't even want to' (AGP7). In such cases, GPs who would usually communicate in Analyse and let choose mode, acte in what they saw as their patient's 'best interests' (toward Be screened or Do not be screened), which could involve no communication, or being selective with the information they shared.
tory of screening (GP has screened the bast or has discussed screening with evidusly, GP knows patient's screening es, of GP knows patient has been or evidusly) 22 23 24 25 26 27 28	Some GPs who would prefer the <i>Analyse and choose</i> approach said they 'may not give a full spiel' (AGP13) to men who have been screened before and 'often do it [discuss] a little more quickly, because it is clear that they remember it from the year before. And if they are men who made the decision last year to have the test done, then they are often going to make the same decision this yearso it's a quicker conversation, but it's not a nonconversation. And it depends on the patient and how well I know them' (AGP30). In these situations, GPs tended to shift to an interaction more like one of the other three approaches. Some GPs were more likely to initiate screening with men who had had PSA screening with them in the past or had had many PSA tests, because 'generally a lot of my patients in now have had the spiel so many times that they often will, come in and say "It's time for my yearly prostate test' (AGP29).
29 stife usual patient of another GP, and ked for a PSA test 32 33 34 35 36 37 38 39 40 41 42	Sometimes GPs who preferred an <i>Analyse and choose</i> approach were consulted by patients who were routinely tested by another GP. In this situation, the GP would assum that the man had heard the talk before. They responded to this situation in several ways Some GPs shifted to either the <i>Be screened</i> or <i>As you wish</i> approach and ordered PSA tests without discussing it with the man, reasoning that the discussion coul be revisited if the PSA was abnormal. Some GPs maintained <i>Analyse and let choose</i> mode and actively engaged patient in a discussion, because they did not know what men had heard from previous GPs. This was sometimes with a view to changing the patient's mind: e.g. 'I am trying to create permission and faith for me to open the discussion up again, rather than just keep redoing the test' (AGP30). Some GPs found this position incredibly challenging if they preferred not to test (i.e. <i>Do not be screened</i>); 'because you have to undo the patient's expectationsyou've got to decided.
43 44 45 46 47 48 49 50	

1	
2 3	whether you just go with the flowor you sit down and ascertain what their appetite for negotiating is. Some of them are just locked into it and it's too late' (AGP23).
s thterested in finding out more about 5 6 7 8 9	 Some GPs reasoned that a man's interest in PSA screening would drive the discussion, 'it tends to be very patient specific and tailored adviceand depends on what I think that they expect and hope to hear and are likely to do' (AGP16). GPs who usually took an As you wish approach, so did not communicate, would in some situations be required to shift to one of the other three approaches (Be screened, Do not
9 10 11	 be screened, Analyse and choose) because the man requested information. Some GPs said the discussion would become 'more complicated' the more interested the patient was.
quested to receive a PSA test or was to be determined to have a test	 These patients were perceived to have positive preconceptions about PSA screening which pre-empt any GP discussion. Some GPs who would usually communicate with a particular goal in mind (<i>Be screened</i> or
16 17 18 19	Do not be screened) said any conversation counter to the man's beliefs was not a productive conversation because their intentions could not be changed; 'they see it as their right to have it [a PSA test]' (AGP15); 'he was so definite he wanted it' (AGP6). GPs tended to take the As you wish approach in these situations, even if this was not their
20 21 22	 To preference. I think that what changes in that situation is their determination to have the testing done, most of these men have made a decision before I've said anything, that they're going to be tested, no matter what I say' (AGP8).
d a family history of prostate cancer 25 26 27	• Conversations with men with family history of prostate cancer were described as being slightly different; some GPs said their interactions with these men would be more 'considered' and 'gentle' despite the majority of the men knowing their decision before coming to the doctor.
28 29 30	• Some GPs who generally communicated in a way to achieve screening (<i>Be screened</i>) or not screening (<i>Do not be screened</i>) changed their approach more towards <i>Analyse and choose</i> and <i>As you wish</i> in situations where a family history was implicated – for both those determined to be tested and those not wishing to be tested.
juggement that the patient was 'very n'agnd had 'done their homework' 34	 GPs were often more inclined to take the option of <i>As you wish</i> in situations involving well-informed men, regardless of the GP's usual practice. Alternatively, GPs might take an <i>Analyse and choose</i> approach and tailor content
35 36 37	accordingly; 'it really depends on the population you're dealing with what you perceive they are capable of understanding' (AGP31); 'You've got to target it at the level of the patient basically' (AGP4).
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41 42 43	
41 42 43 44 45 46 47	
47 48	

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Primary goals, information-giving and men's understanding: a qualitative study of Australian and UK doctors' varied communication about PSA screening

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SCHOLARONE™ Manuscripts Primary goals, information-giving and men's understanding: a qualitative study of Australian and UK doctors' varied communication about PSA screening

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Abstract

Objectives:

- To characterise variation in general practitioners' (GPs') accounts of communicating with men about prostate cancer screening using the PSA test;
- 2. To characterise GPs' reasons for communicating as they do; and
- 3. To explain why and under what conditions GP communication approaches vary.

Study design and setting: A grounded theory study. We interviewed 69 GPs consulting in primary care practices in Australia (n=40) and the United Kingdom (n=29).

Results: GPs' explained their communication practices in relation to their primary goals. In Australia, three different communication goals were reported: to encourage asymptomatic men to either have a PSA test, or not test, or alternatively, to support men to make their own decision. As well as having different primary goals, GPs aimed to provide different information (from comprehensive to strongly filtered) and to support men to develop different kinds of understanding, from epidemiological to 'gist' understanding. Taking into account these three dimensions (goals, information, understanding), and building on Entwistle et al.'s (2008) Consider an Offer framework, we derived four overarching approaches to communication: Be screened, Do not be screened, Analyse and choose, and As you wish. We also describe ways in which situational and relational factors influenced GPs' preferred communication approach.

Conclusion: GPs' reported approach to communicating about prostate cancer screening varies according to three dimensions—their primary goal, information provision preference, and understanding sought—and in response to specific practice situations. If GP communication about PSA screening is to become more standardised in Australia, it is likely that each of these

dimensions will require attention in policy and practice support interventions.

Strengths and limitations of this study

- Qualitative methodology is well-suited to investigating complex multifaceted processes, like communicating about PSA screening from the perspective of clinicians, and preserves important contextual information relating to the process.
- Data were derived from a large, rigorously derived sample of GPs from different practice
 types and locations, and in two countries. The four approaches identified in this study may
 be applicable to a wide range of practice settings.
- It is possible that those GPs who did not participate were in some way different to those who did (that is, that these data are subject to selection bias), however the diversity in our respondents suggests that it is very unlikely that our sample was biased towards a particular view of PSA screening or corresponding communication style.
- As this is a qualitative study, we cannot infer prevalence of the four reported approaches;
 the results of this study could be extended into quantitative survey research with whole
 populations of GPs to test prevalence.
- Public and patient perspectives were not included in this study; additional qualitative
 research might explore their experiences of communicating with clinicians about prostate
 screening, to further inform policy and practice.

Introduction

Worldwide, many men undergo regular prostate-specific antigen (PSA) screening for prostate cancer risk in primary care. We will use *PSA screening* to refer to PSA testing in ostensibly healthy men who are not considered to be at high risk of prostate cancer for their age; this contrasts with PSA testing in men who have a diagnosis of prostate cancer or are experiencing acute symptoms that may suggest prostate disease. Although the value of the PSA test as a screening tool is scientifically contentious, the public perception of prostate screening is reportedly positive, including an inflated sense of the benefits and underestimation of the harms (1). Access to a PSA test is often via General Practitioners (GPs). The large number of men screened in some countries, and the extent of public misperception and scientific contention, make the communication between men and their GPs about prostate cancer screening especially important.

Communicating about screening is difficult. In-depth discussions about cancer screening can be complex, and may involve multiple statistical concepts, such as test sensitivity and specificity, and absolute and relative risk reduction figures from trial-based evidence. Chan et al. identified over 20 specific informational items that experts and patients identified for inclusion in an 'ideal' discussion about prostate screening (2). The authors synthesised the items into a core set of key facts that clinicians should provide about PSA screening to their patients (Figure 1, developed by KP), however we note that even some of these items are contentious or inconsistent with the various national guidelines that we will discuss in the next section.

Insert Figure 1 about here

Proposed communication standards for PSA screening discussions are reportedly challenging to implement in clinical practice e.g. (3-5). PSA tests are often ordered in the absence of any discussion; in the US, men report being unaware of being screened (6), not being asked for their screening preferences, and undergoing PSA testing without first discussing it with their doctor (7). Clinicians report offering screening without prior counselling (8). A survey of US physicians

reported 20% acknowledged ordering PSA without telling patients (9). This can be for various reasons (10). Volk et al. surveyed US physicians and found that those physicians who reported ordering PSA tests without discussion were more likely to believe that patients wanted to be screened and that education is not needed. This was in contrast to those physicians who engaged patients in pre-screening discussion because they believed patients should know about the lack of evidence supporting screening (11). Physician beliefs about the limitations of the scientific evidence for PSA screening, the questionable utility of the PSA test, and ethical concerns regarding patient autonomy have also been identified as influencing the likelihood of discussions in US studies (10, 12). Physician beliefs can shape the content of discussions; in a UK study, the strong personal views of clinicians against the value of PSA screening were reportedly clearly portrayed in their presentation of information about prostate cancer screening (13).

In addition to this work on physician knowledge, values and attitudes, some researchers have studied patient and practice factors that may facilitate or preclude discussions about prostate cancer screening. For example, in one study US physicians were less likely to discuss screening if a patient had already made a decision about screening, or was perceived to have limited ability to understand the information (10). Other studies have reported on factors affecting the quality of discussions, including a lack of time and the complexity of the topic (9).

Clinicians have cited clinical guidelines and scientific evidence about prostate cancer screening as factors guiding their practice e.g. (13). However this professional guidance varies widely, which may partly explain the observed variation in practice. Table 1 outlines the recommendations of key professional organisations in relation to communicating about prostate cancer screening, illustrating the main points of difference. "Informing" men about the benefits and harms of PSA screening is universally recommended; and use of decision support tools is recommended by half of the professional organisations. Only four of the ten guidelines advise whether GPs should raise the topic of PSA screening with men who do not ask about it in routine consultations. Medico-legal issues are referred to in only one, Australian, guideline. In practice,

clinical guidelines may not always help GPs to decide how and what to communicate about PSA screening (14).

Insert Table 1 about here

Entwistle et al. characterised the two main ways that health care organisations communicate with the public about screening – *Be screened* and *Analyse and choose* – and proposed an alternative approach to communicating about screening, which they termed *Consider an offer* (15). The *Consider an offer* approach suggests health care providers should support people to assess an offer for screening, with a recognition that people may reasonably decline such offers. *Consider an offer* guides clinicians and patients to consider the source of screening recommendations and professional guidance. We return to the *Consider an offer* approach in the Discussion.

This study draws on a larger body of work investigating clinician's approaches to, and reasoning about, PSA screening in Australian and UK general practice. Despite similar levels of prostate cancer mortality, both PSA screening and prostate cancer incidence are lower in the UK than in Australia (16-19). Previous analyses from this study have illuminated systemic variation between the two jurisdictions, including in payment models, the history of PSA screening policy, screening culture, and referral patterns (14). The authors have also published earlier findings from the empirical work about how clinicians manage the potential for overdiagnosis (20) and their responses to uncertainty in relation to prostate screening (21). Table 2 summarises our previous findings regarding differences in PSA screening in the two jurisdictions. Note that prostate cancer screening is not recommended in either location.

Insert Table 2 about here.

In the light of our prior findings on variation between the Australian and UK contexts, we set out to better understand GP communication practices in particular. The larger program of study examined the role of values, ethics, context, and evidence in cancer screening policy and practice. In this paper we present an analysis of how GPs in Australia and the United Kingdom

explain their approach to communication with men about prostate cancer screening. We asked the following research questions, in respect of both settings:

- 1. How do GPs describe their communication with men about prostate cancer screening?
- 2. What are the reasons given by GPs for communicating with men as they do?
- 3. Why and under what conditions do GPs communication approaches vary?

Methods

Ethics approval

Study procedures were approved by the Cancer Institute New South Wales and the University of Sydney Human Research Ethics Committee [#15245]. GPs had an opportunity to discuss the study with KP prior to participation; all GPs provided informed written consent to participate and were compensated for their time. Participation was voluntary, participants could withdraw at any time, and confidentiality was protected. All responses were anonymised before analysis and potentially identifying information removed.

Design

We applied the well-established, systematic qualitative research methodology of grounded theory (22). Grounded theory is a method of conducting qualitative research that focuses on creating conceptual frameworks or theories through building inductive analysis from the data. All study authors have been formally trained in qualitative research methods; SC has particular expertise in grounded theory methodology.

Participants and Setting

We identified clinicians working in primary care practices as being in the best position to provide insight on our research questions, and most likely to face the question of PSA screening as part of their everyday practice. We purposively recruited a sample of GPs first in the Australian health care setting, and later in the United Kingdom (England, Scotland, and Wales), as our study evolved. Sampling for the broader study was initially driven by existing quantitative evidence on characteristics of GPs, patients, and practice contexts associated with higher or

lower PSA screening rates. We aimed to recruit a set of GPs likely to have diverse practices. See Pickles et al. (14) for a detailed description of the recruitment process.

In Australia we advertised in newsletters and email lists of GP organisations, in mass and social media, medical journals, we phoned practice managers and via email and flyers distributed by rural GP organisations. In the UK, academic colleagues distributed an invitation through their professional networks, we advertised to members of the Royal College of General Practitioners (RCGP), primary health care departments, university academic departments, and general practice and research via mail lists, and in organisational newsletters including the Society for Academic Primary Care (SAPC) and RCGP Scotland's eBulletin. GPs were invited to contact KP if they were interested and willing to participate. An information sheet outlining the research project was emailed to all respondents. All GPs who expressed interest in participating were included.

Overall, 69 GPs participated in this study, 40 GPs in Australia and 29 GPs in the UK. 44/69 of the GPs were male. The GPs ranged in clinical experience, working from 1-40 years in general practice, and were located in both metropolitan (n=32/69) and regional/rural (n=37/69) clinics, with varied patient populations.

Data collection

The field work for the prostate cancer element of this study was conducted by KP, a public health researcher, as part of a PhD degree. KP had no immediate personal or professional experience with prostate cancer or PSA screening.

We generated data via in-depth semi-structured interviews. An interview guide was prepared to provide general direction and an overview of potential question routes. The interview guide covered a broad range of topics, including GPs' recent clinical encounters involving PSA screening decisions, communicating information about the PSA test to patients; screening pathways; and overdiagnosis of prostate cancer. Example questions asked about communication included:

- Describe a recent consultation with an asymptomatic man involving the PSA test...Can
 you take me right back to the beginning and tell me as much as you can about the
 consultation. Who initiated the conversation about the PSA test?
- Should men be informed about overdiagnosis, false positives before having a PSA test?
- How well do you think men understand PSA screening?

The schedule was reviewed and modified between interviews based on the developing analysis to enrich the data available to answer our research questions. All GPs were asked to think back to their most recent consultation involving a discussion about PSA screening or to describe a typical consultation where the topic was raised.

Interviews took place between March 2013 and June 2014 (Australian GPs) and between September and December 2014 (UK GPs). We continued to interview GPs until we judged we had reached theoretical saturation; that is, the point at which gathering more data ceases to yield any further insights about the emerging grounded theory. All interviews were conducted by KP, primarily by telephone or Skype, and ranged in duration from 18 to 70 minutes. With GP permission, the interviews were audio-recorded and transcribed verbatim by a professional transcribing service to produce data for analysis. Transcripts were not returned to participants for comment; all participants will receive a written summary of the research findings on study completion.

Data coding and analysis

The analysis was led by KP, who coded the transcripts. A subset of transcripts was read and coded by three authors independently to ensure interpretive rigor. We coded to capture the range of variation in the GP-reported discussions about PSA screening and for conditions that could explain that variation. Codes were kept as similar to the data as possible to preserve context and to ensure that all concepts derived directly from the data. Codes were compared and discussed to inform the development of the central concepts in the study. KP wrote detailed

memos during data collection and analysis which were reviewed and discussed by the authors in analysis meetings.

Results

We observed considerable diversity in the ways that GPs' described their communication about prostate cancer screening. Although the majority of variation occurred among Australian GPs, we also report on data from the UK because this helps illuminate the contrasting complexity of the Australian data, including the role of local context.

We first explain how Australian GPs' varied in their descriptions of their communication. In the second section, we consider important ways in which UK and Australian GPs were similar and different.

Australian GPs' reported communication with men about prostate cancer screening

Australian GPs' accounts varied greatly in how they introduced conversations about PSA screening with men, how screening discussions were framed, and their perceived informational obligations.

Screening men with little or no prior communication

A minority of interviewees reported ordering PSA tests for asymptomatic men with little or no prior communication with the patient. GPs were categorised as non-communicative if they reported (1) ordering PSA tests without explaining that to their patient, (2) ordering PSA tests at patient request with no further discussion, or (3) explaining PSA screening only after a positive PSA test result. We encountered occasional practices from which asymptomatic men were mailed pathology forms for a PSA test via practice recall systems, bypassing a GP consultation and opportunity for discussion.

Several possible justifications were provided by non-communicative GPs:

• Some GPs reasoned that because the information about PSA screening was 'confusing' 'complicated' and potentially contradictory, it should not be provided.

- Some GPs said their role was to ensure that men could be screened if they wanted, 'I see doctors purely as enablers, of what people want...If you don't want to read about it [the test], then fine; I'll just order one for you' (AGP17).
- Some GPs considered it 'up to each patient to be informed appropriately' (AGP14); if a
 man requested a PSA they would order a test assuming that man felt sufficiently
 informed from other sources.
- Some GPs considered it unnecessary to provide information unless the man received a cancer diagnosis, 'I don't think they need all that information at the level of PSA testing. I think, that once you've got your cancer diagnosis, you can talk about what you want to do with that then' (AGP26).
- Some GPs did not appear to have a complete understanding of the epidemiological data, for example, 'someone was saying that a certain number of people had to have radiation and surgery and have impotence and incontinence, for one person's life to be saved. I mean I don't know how you get those figures' (AGP2).

These were, however, minority views. We focus in what follows on the majority of GPs who *did* communicate with men in some way about PSA screening.

Communicating with men, with variation on three key dimensions

We identified three dimensions central to GP discussions with men about PSA screening:

- The GPs' primary communication goal. Some GPs had the goal of convincing the patient
 to screen, some had the goal of convincing the patient not to screen, and some had the
 goal of supporting decisions or facilitating patient choice;
- 2. The type of information the GP provided; and
- 3. The type of patient understanding the GP sought to achieve.

It appeared that Dimension 1 was dominant; GPs communicated in accordance with their preferred goal or outcome of the communication. In most cases, the GP's positioning on dimensions 2 and 3 was grounded in whether the GP felt strongly that patients should be

screened or not, and the degree to which they directed men towards that preference. Below we explain these three dimensions, and GPs' reasoning about them.

Dimension 1. GP's primary communication goal

Some GPs aimed to convince men either to agree to be screened, or to agree not to be screened. These GPs had strong beliefs regarding whether or not PSA screening should occur routinely, and wanted patients to follow their advice, their 'guide...down the path' towards what they 'thought was best' (AGP29). GPs acknowledged 'bias will creep into that' (AGP29); 'you can't help yourself but...what you believe in is the way you push the consultation' (AGP18). However this approach was justified by beliefs that, '...you can only do what you think is best for the patient' (AGP29) and 'a lot of people do want to be told what to do...doctors are their reference point' (AGP31). GPs recognised that men sometimes chose not to take the advised pathway, for example, 'there are times when it wouldn't matter what you said to a patient they're still determined to have the test' (AGP18).

An alternative communication goal was to support men to make decisions about screening consistent with their own values and preferences. GPs with this goal aimed to facilitate an informed decision making process and were determined to provide information to all men 'to make up their own mind' (AGP16), because 'with the PSA test, I can't so easily say to myself, well, it's in your best interests so I don't need to inform you properly' (UKGP9). GPs with this goal reasoned that a man 'should be empowered to know everything' (UKGP28); 'should have the right and want to be able to make that decision for themselves about whether they have the test or not' (AGP5).

Dimension 2. GPs' reported information provision

Because GPs had different goals in communicating, they provided different information, in both quality and quantity.

Some GPs claimed to provide men with 'complete' and 'unbiased' information, because they considered it their 'ethical obligation' as a health professional to do so; the patient, in this view, had a 'right' to be fully informed, so GPs should '[put] all the information on the table' (AGP31); 'I'm very keen that people are well-informed about really what it means if they are to undertake a PSA rather than just simply agreeing to what their idea might be' (UKGP23). This sometimes

extended to teaching patients how to locate and interpret information for themselves. Informing patients was described by some GPs as serving a self-protective legal purpose, *T've informed the patient, the patient made his own decision, so he's got to then accept the consequences'* (AGP19).

In contrast to GPs who sought to provide comprehensive information, other GPs filtered information to 'actually tell them [patients] what counts the most' (AGP4). Here GPs aimed to explain their own best judgment about the evidence, framing the evidence according to the GP's opinion regarding the value of PSA screening. This often took the shape of a personal recommendation either to have a PSA test or not. One GP, for example, said '[patients] don't have that knowledge so you sort of, give an explanation why it needs to be done' (AGP35); another, in contrast, thought 'my discussing it has probably been biased towards not getting it done' (AGP16). Some GPs considered such advising to be best practice, because information provision alone was not enough to help men decide what to do. For example, one GP who favoured PSA screening reasoned, 'If they really don't know what to do then [after receiving information], any doctor would be a fool not to say look, get it investigated because, the most stupid thing anyone could do is say oh don't bother about it...that's just a total recipe for disaster' (AGP31).

Dimension 3. GPs' reported ambitions for men's understanding

All GPs aimed to support the development of patient understanding. However there were two different conceptions of what constituted appropriate understanding of the information presented and available options:

1) Sometimes GPs aimed to assist men to develop detailed *epidemiological understanding* of the evidence. They wanted men to understand all aspects of the information provided and described checking understanding, identifying gaps in patient knowledge, and clarifying misunderstandings, because 'I don't think their pre-existing understanding of the test is very good at all in most cases' (UKGP21). Some of these GPs reported feeling personally and professionally responsible for presenting the 'right amount' and 'right level' of information for individual patients, '[achieving understanding is] really the doctor's job, and our skill in trying to explain all that complicated evidence, as best as we can' (AGP19). Some GPs commented they hoped men

understood the detail of the evidence, otherwise it indicated they as a GP had done a 'bad job of explaining it' (AGP6), however they also explained 'it's a very difficult thing to formally confirm that they understand the implications of having the test done without kind of interrogating them' (UKGP1).

2) Alternatively, GPs might aim for men to develop overall 'gist' understanding. GPs committed to 'gist' understanding were satisfied if their patient had a less complete grasp on the intricacies of the evidence base, as long as they had an overall understanding of what the GP perceived to be core issues; 'I feel like as long as they can understand that basic concept [in this instance, that PSA is not a perfect test] ...then I feel like it's okay to still do the testing, even if they don't understand all the detail...I feel like that's a reasonable level of understanding, I don't feel like people need to have an absolutely thorough kind of understanding' (AGP5). Those GPs who thought 'gist' understanding was acceptable thought it was reasonable for men to trust their doctor to advise them appropriately.

Relationship between the dimensions

When taking account of the three dimensions along which GPs varied, we identified four overarching approaches to communication: (1 & 2) *Be Screened* and *Do not be screened* (GPs who guided men towards screening or not screening); (3) *Analyse and choose* (GPs who aimed to ensure men made their own independent, informed decision, based on a detailed epidemiological understanding); (4) *As you wish* (GPs who simply facilitated the man's stated preference to be screened or not screened). Two of these terms (*Be Screened* and *Analyse and choose*) align with Entwistle et al.'s characterization of communication approaches (15), as outlined in the introduction. Each GP we interviewed had a general preference to employ one of these four approaches in their everyday communication about PSA screening. In Table 3 we present an integrated illustration of the characteristics of each approach, ordered according to the 3 key dimensions evident in the GP accounts.

Insert Table 3 about here.

Be Screened or Do not be screened interactions. If GPs had a strong preference that men should either be screened or avoid screening, they communicated in a directive way, oriented to encouraging the man either to screen or avoid screening respectively. This included offering personal judgment about the value – or harms – of PSA screening or framing the information they provided towards or away from screening. Some GPs gave a recommendation without offering men any further information. In Be screened and Do not be screened interactions, GPs considered it sufficient that men developed gist understanding of the information provided, because they thought it was reasonable for men to trust their doctor to advise them appropriately. These GPs strongly believed either that men should be screened routinely, or that they should not be screened at all, and they wanted patients to follow their advice.

Analyse and choose interactions. If GPs aimed to support men to make their own decisions, consistent with the man's personal preferences (i.e. a patient-directed decision), then they were not directive in their communication. In these interactions, GPs aimed to provide a comprehensive and impartial summary of the best available evidence; their goal was to ensure that men developed a detailed epidemiological understanding of their options in order to make an informed decision. They saw this as a neutral, educative role. For some, this approach was protective against potential medico-legal threats. GPs using this approach may personally favour either screening or not screening, but their primary commitment was to support the man's decision, regardless of their own professional beliefs about screening.

As you wish interactions. Sometimes GPs acted on patient wishes to be screened or not screened without questioning. In these interactions GPs did not attempt to direct men in any particular direction, and often provided little information, ensuring that the man understood PSA screening was not a priority. In some cases, GPs perceived men to have already made a screening choice based on personal preference or gist understanding. These consultations typically involved men with an already-established screening preference, mostly for screening; the GP simply acted in line with the man's instructions.

How GPs negotiate communicating within specific contexts

Many Australian GPs reported discussing PSA screening with men often, so had a prepared basic 'spiel'; as one reported, 'the PSA is such a common question that you get asked and you just have to have some idea in your head what you're going to say when they come in' (AGP18). This spiel could be tailored to specific contexts as necessary. GPs' interviews indicated that they tended to have a preferred approach for most PSA interactions (to guide patient toward screening or not screening, to support men to make their own decision, or to act in accordance with the man's expressed preference), or that they had maintained a particular communication style over time. However we identified eleven situational and relational factors (see Table 4) that GPs described as temporarily shifting their usual or preferred communication goals and processes. These factors predominantly arose from specific circumstances of individual consultations. GPs described modifying their provision of information and/or advice, depending on the eleven factors described in Table 4.

Insert Table 4 about here

GPs also shifted between the four communication approaches more readily when they were presented with complex cases; producing more fluid, responsive, and sometimes 'quite inconsistent' (AGP16) conversations. Many GPs did have a primary goal when communicating (to encourage or discourage screening, or to support the man to make his own decisions) but these could change in different situations. Also, some men did not take the advised pathway – either toward screening or not screening, or some men preferred the GP to direct the decision, not wanting to engage with information or to make their own decision.

Comparison of communication approaches in Australia and the UK

UK GPs generally did not communicate about PSA screening unless men asked about it, so they often neither communicated about it as a screening test, nor ordered it. When men asked for a PSA test, information provision was central to consultations in the UK context, and most UK GPs

commonly practiced according to the *Analyse and choose* or *Do not be screened* approaches. Few UK GPs described adjusting their conversations about PSA screening with patients.

The reported consistency of PSA communication practices in the UK contrasted strongly with the significant variation reported in the Australian context (Tables 3 and 4). The contextual factors considered in Table 4 were uncommon in UK GPs' accounts, due to fewer men requesting and fewer GPs suggesting prostate screening. UK GPs mostly reported giving the same standard information leaflet to all men who expressed interest in PSA screening, regardless of their personal circumstances. Many GPs practicing in Australia tended to filter information, and commonly practiced according to the *Be Screened* approach, but no UK GPs reported using this approach.

We identified different versions of the *Do not be screened* approach adopted by Australian and UK GPs. For the Australian GPs, this approach took the form of a personal recommendation against screening, directed by the GP and according to their personal – negative – perspective of PSA screening. For UK GPs, the *Do not be screened* approach also involved the GP recommending that the man should not be screened. However UK GPs explained this as enactment of a collective standard of care recommended and issued by the UK National Health Service irrespective of their own personal preferences for or against screening.

Discussion

This analysis suggests that GP's primary communication goals are a central component of consultations about prostate screening. Four distinct communication approaches – *Be Screened*, *Do not be screened*, *Analyse and choose*, and *As you wish* – were identifiable from GPs' accounts of their preferred practice.

The terms *Be Screened* and *Analyse and Choose* align with Entwistle et al.'s Consider an Offer framework. We identified two additional ways of communicating unique to our empirical data, which we labeled *Do Not Be Screened*, and *As you wish*. The need for inclusion of a *Do not be Screened* element is likely a product of the Australian context where the PSA test is available and widely promoted for screening purposes in the media, despite the majority of relevant public

health and health professional groups recommending against routine screening of asymptomatic men. This meant Australian GPs were regularly consulted by men expecting to be screened, and some reported feeling obligated to actively direct men away from wanting a PSA test for that purpose.

The *As you wish* category is also likely to be, in part, a reflection of the somewhat market-driven Australian health care system. *As you wish* interactions occurred when GPs' believed men had already made up their minds about their preferred choice, and could not be swayed by information presented by the GP. This led GPs to implement the man's choice and order the test, despite the lack of an evidence base to support that decision. There was no evidence of *As you wish* interactions in the UK data. As we previously reported (14), in the UK there is strong guidance to GPs to practice in a particular way. GPs are expected to steward limited NHS resources, and the PSA test is not publicly promoted to the same extent, limiting consumer expectations for screening. All of these are conceivable explanations for why *As you wish* interactions were less commonly reported in UK interviews.

The main issues raised by this analysis

The four variants raise important questions about patient-centered care, consumer demand, and the role of the health professional. It is well established in the literature that both patients and clinicians are rarely entirely rational, and may not necessarily know what is in the patient's best interest, particularly when faced with scientific uncertainty e.g. (23, 24). Humans tend, for example, to become sensitised to worst-case scenarios and disregard objective risk probabilities; this makes us vulnerable to pursuing, recommending, or accepting potentially harmful treatments (25). If this is so, an *As you wish* approach could mean patients are more exposed to increased harms, and that leaving patients to make decisions about their health care needs without professional guidance is potentially maleficent, or at least negligent. This problem is further complicated by the wide availability of possibly misleading information, provided by sources that have an interest in inflating perceptions of cancer risk. Some authors highlight that increased patient involvement in decision making has potential for negative social consequences

such as increasing patient demand for unproven services (26). Cribb and Entwistle reasonably argue that in some circumstances it may be ethically legitimate for health professionals to question and even influence the preferences of patients for these reasons (27).

Most current recommendations encourage GPs to discuss the benefits and harms of prostate cancer screening with patients. However, there may be considerable variation in what patients want and expect from GPs prior to making a decision about PSA screening. Degeling et al. ran three community juries on the topic of how GPs should communicate about PSA screening. Juries heard extensive expert evidence about PSA screening, consent and general practice. Two juries of general citizens (i.e. mixed gender and age) concluded that GPs should ensure men have enough knowledge to make their own decision. One jury of only men of PSA screening age concluded that men should be able to trust their GP (or a specialist) to provide just enough information at just the right time, expressed concern about the potential for information overload, and thought the degree of patient involvement depended on the patient (28). This suggests that citizens who are (atypically) well-informed about the benefits and harms of prostate cancer screening may take different views and have different expectations on how GPs should communicate about PSA screening. If this is the case, it may be appropriate for GPs to have at least a range of communication strategies available, to suit the needs of different patients. Men eligible for, or already receiving, PSA screening, may well prefer for GPs to direct the decision (Be screened or Do not be screened approaches) to avoid uncertainty. However men's preferences are arguably an insufficient guide; other considerations, including clinical practice guidelines, medical law and clinical ethics requirements, are relevant to determining what GPs should do.

A large component of this analysis is about awareness of and sensitivity to context and the importance of interpersonal relations and their influence on communication practice (see Table 4). Some of the GPs' communication decisions, based on situational or individual factors, were easily justified, because the situation presented was either clinically relevant (e.g. family history, older age), or professionally justified (e.g. low literate patient, patient request). While most

guidelines advising on PSA screening suggest informed or shared decision making, they do not consider what may be a 'best' approach to situations involving the many local factors that GPs' face in day to day practice, including relational factors, implicated in screening decisions (and the complexities of general practice). We identified a subtle web of relational issues that influenced GPs to move between communication options and particular types of decision pathways. These included managing colleague associations (what are GPs to do about patients who have come from a pro-screening GP to a GP who does not support PSA screening?), managing business, including patient lists (patient request, time pressures), and maintaining patient trust. These issues made the decision making process particularly complicated, and in addition to vague guidance on such matters, perhaps account for why many GPs appeared to have multiple, dynamic approaches. Accounting for relational variables as identified in this study can facilitate nuanced assessment of the different types of support clinicians might offer people who may struggle with particular decisions (29), and allows scope for professional expertise; the 'art' of medicine.

Implications for policy and practice

There are variable approaches to communication about PSA screening, some of which may be considered better than others. Guidance about communication - not just about the PSA test itself, but also about how best to facilitate the decision – may be useful; we suggest there is a need for further higher level professional discussions about what the primary goals of GPs should be when communicating about PSA screening. Coming to an explicit agreement on what that purpose should be may assist in improving communication and providing clearer guidance for GPs working in the Australian context. For instance, one endpoint (that could be evaluated) may be that men can demonstrate they have a sense of their values in relation to the available options, to show evidence of rational, thoughtful, and informed decision making.

Limitations

As this is a qualitative study, we cannot infer the prevalence of the reported approaches to communication; the results of this study could be extended into quantitative survey research

with whole populations of GPs to test prevalence. It is also possible that those GPs who did not participate were in some way different to those who did (that is, that these data are subject to selection bias), however the diversity in our respondents suggests that it is very unlikely that our sample was biased towards a particular view of PSA screening or corresponding communication style.

Conclusion

This empirical study produced evidence documenting varied approaches to communication. In the Australian setting, some flexibility in communication seems justified. Further, because of (a) the large number of men implicated, (b) the known harms of the screening process, and (c) that PSA is not a routine screening program, we argue that PSA screening is a particularly pressing case to necessitate dedicated effort to facilitate conversations that include but go beyond potential harms and benefits with men. This would include encouraging and enabling men who ask for screening to look carefully at why PSA screening is not recommended (to increase awareness of why a *Do not be screened* approach is justified). Assisting GPs to facilitate these conversations with patients should offer the advantage of supporting men's autonomy and reducing harm.

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Transparency: KP affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; no important aspects of the study have been omitted.

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Ethical approval: All study procedures were approved by the Cancer Institute NSW and the University of Sydney Human Research Ethics Committee [#15245]. Each participant gave signed consent prior to the interview.

Data sharing: No additional data available.

Contributorship: KP, SC, and LR conceived the study and were involved in designing the study and developing the methods. SC & LR obtained funding and were CIs on the NHMRC funded project grant; VE was an AI on the project. KP conducted the interviews, had full access to all data in the study, and takes responsibility for the integrity of the data and the accuracy of the data analysis. KP drafted the manuscript. All authors (KP, SC, LR, KM, VE) contributed to the interpretation of the analysis and critically revised the manuscript.

Figure 1.

TITLE: Proposed content for informed consent for PSA screening (Chan et al., 1998, figure developed by KP)

LEGEND: Chan et al. identified a core set of key facts that clinicians should include in an 'ideal' discussion about PSA screening



Table 1. The recommendations of professional organisations in terms of communicating about prostate screening

ed in recommendation and guidance 6	Professional Organisation									
	PCFA/CCA1	NHMRC ²	RACGP ³	USANZ ⁴	NICE5	NHS/PHE6	USPSTF7	ACS ⁸	NCI ⁹	Al
o ए t whether to raise the if 8 en do not raise it first?			✓		✓	✓	✓			
9 recommended?	1	1	✓		1					
11 Гриоуided?		1				1				
— 13 ien(d≱d? — 15	1	1	1	1	✓	1	1	1	✓	
ոе մ © ed? 17			√		✓		✓			
om pg inied by a clinician et¶9	1	\				✓	✓			
on ያຜ nied by a patient et 2 4		1	1		1	1				
reanmend clinician to share craning decision?							1			
24 o- ½5 al responsibilities?			1							

tate Gancer Foundation of Australia/Cancer Council Australia al Health and Medical Research Council Istrafian College of General Practitioners

cal **29**ciety of Australia and New Zealand

nal**30**stitute for Health and Care Excellence

⁶ NHS/PHE: National Health Service/Public Health England

⁷ USPSTF: United States Preventive Services Task Force

⁸ ACS: American Cancer Society

⁹ NCI: National Cancer Institute of the National Institutes of Health

¹⁰ AUA: American Urological Association

be 🔏 on Making (IDM): The patient is presented with all the information pertinent to making a decision and then assumes final authority for the decision (30). ris🚱 Making (SDM): The patient is provided with all the relevant information and works with the health care provider to reach a decision that reflects the healt ofthe patient (30).

information sheet is a fact sheet summarizing the evidence of benefits, limitations, and associated risks of prostate screening to help clinicians to accurately info

35 aforganation sheet is a fact sheet outlining the benefits, limitations, and associated risks of having a PSA test for prostate cancer risk.

Table 2. The organisation and occurrence of PSA screening in Australia and the United Kingdom [summary of findings, details reported in Pickles et al 2016]

•	Australia	United Kingdom
For men asking about prostate screening	PSA screening is available. GPs are advised to offer evidence-based decisional support to men considering whether or not to have a PSA test, including the opportunity to discuss the benefits and harms of PSA screening before making the decision.	PSA screening is available, but with conditions. The National Health Service Prostate Cancer Risk Management Programme (PCRMP) has recommended that screening for prostate cancer be available for asymptomatic men, on the understanding that they have been provided with full and balanced information about the advantages and limitations of the PSA test.
Screening frequency	 GPs reported frequently providing PSA screening within routine consultations. GPs reported often initiating discussion of PSA screening; GPs reported commonly receiving requests for PSA screening. 	 GPs reported that PSA screening was rare in practice. UK GPs reported not promoting PSA screening; they also reported that men rarely asked for PSA screening.
Guidance for GPs	 GPs are free to practice according to individual standards. Australian guidance was mixed (see Table 1). The NHMRC has recently issued guidance to Australian GPs to drive greater consistency in practice. 	 Government-issued standards for PSA screening and communication processes in clinical settings are in place. Guidance has been distributed to all GPs in England and Wales to assist in the provision of information to men. GPs can choose to follow issued guidance but seem inclined to operate within the bounds of their health system.
Preferred form of information provision	GPs reported generally informing men via a verbal discussion of PSA screening.	GPs reported relying on a standardized printed information leaflet. This was central to the consultation, sometimes alongside a brief verbal discussion.
Appointment structure	PSA screening tests were usually discussed and ordered in a single appointment.	Information-giving occurred in a separate appointment to PSA screening itself.

Table 3. Four GP approaches to communication about PSA screening in clinical interactions

BE SCREENED interactions

GP's primary goal:

- GP strongly believed that the man should be screened
- GP goal is to convince the man to screen

Information provided by GP:

- GP's personal judgment about the value of PSA screening
- GP either tailored information provided to men to encourage men to be screened, or did not provide information (provided only encouragement to be tested)

Type of understanding that GP considered adequate:

Gist understanding of information provided

ANALYSE & CHOOSE interactions

GP's primary goal:

- GP may personally support testing or not testing
- Despite their personal beliefs about testing, GP's goal is to help the man to make his own informed decision

Information provided by GP:

 GP aimed to provide a comprehensive and impartial summary of best available evidence

Type of understanding that GP considered adequate:

 GP goal was to ensure men developed detailed understanding of their options, to make own informed decision

DO NOT BE SCREENED interactions

GP's primary goal:

- GP strongly believed that the man should not be screened
- GP goal is to convince the man not to screen

Information provided by GP:

- GP's personal judgment about the harms/downsides of PSA screening
- GP either tailored information provided to men to discourage screening, or did not provide information (provided only encouragement to avoid testing)

Type of understanding that GP considered adequate:

• Gist understanding of information provided

AS YOU WISH interactions

GP's primary goal:

- GP may or may not have a strong position on the value of PSA screening
- GP's goal is simply to follow the man's expressed preference

Information provided by GP:

GP provided little information

Type of understanding that GP considered adequate:

 Ensuring men understood was not a priority for the GP. In some cases, GP perceived men to have already made a screening choice based on personal preference or gist understanding

3	
ou¶aged particular approaches to t P§A screening, as described by GPs	Examples of how GPs reported modifying their communication
6	SITUATIONAL FACTORSpertaining to patient and/or GP
def or younger age group years or over 75 years), or had 9 10 11 12 13 stopy of prostate cancer 15 16 17 18 ceeive a PSA test or was perceived to	 Some GPs paid closer attention to which direction they 'coaxed' patients in these age groups; for example, some we emphasise false positives and the potentially harmful diagnostic pathway to younger men under 50 years (i.e. GP n Do not be screened approach). Some GPs who usually communicated in Be Screened mode provided comparatively less detailed information for o particularly those with declining memory or those they perceived as being cognitively unable to 'handle the inform 'pick[ing] the details of the intricaciesand a lot briefer [conversation]' (AGP17) Some GPs described defaulting to providing stronger recommendations with elderly men. Conversations with men with family history of prostate cancer were described as being slightly different; some GP interactions with these men would be more 'considered' and 'gentle' despite the majority of the men knowing their coming to the doctor. Some GPs who generally communicated in a way to achieve screening (Be screened) or not screening (Do not be screening approach more towards Analyse and choose and As you wish in situations where a family history was implicated determined to be tested and those not wishing to be tested. These patients were perceived to have positive preconceptions about PSA screening which pre-empt any GP discussions.
a lest 21 22 23 24 25	 Some GPs who would usually communicate with a particular goal in mind (Be screened or Do not be screened) said counter to the man's beliefs was not a productive conversation because their intentions could not be changed; 'they right to have it [a PSA test]' (AGP15); 'he was so definite he wanted it' (AGP6). GPs tended to take the As you wish approximations, even if this was not their preference. 'I think that what changes in that situation is their determination to have the testing done, most of these men have made before I've said anything, that they're going to be tested, no matter what I say' (AGP8).
inggrding out more about screening 27 28 29 30	 Some GPs reasoned that a man's interest in PSA screening would drive the discussion, 'it tends to be very patient speadviceand depends on what I think that they expect and hope to hear and are likely to do' (AGP16). GPs who usually took an As you wish approach, so did not communicate, would in some situations be required to shother three approaches (Be screened, Do not be screened, Analyse and choose) because the man requested informati Some GPs said the discussion would become 'more complicated' the more interested the patient was. SITUATIONAL FACTORSpertaining to service characteristics
31 ited access to urology services 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47	 Some GPs were influenced by their access to a Urologist. Although they might prefer to recommend that men Be Sc be screened, they described instead shifting their approach towards Analyse and choose when based in a rural locat try to explain the test, do a bit more pre-test counselling with the patient when I was in the country, just because I kne managing the result rather than just sending them onto a Urologist, like it's easy to do in Sydney' (AGP5). GPs describ locations it is common for GPs to have to manage abnormal PSAs for a longer period before they can access urologi opinion. Some GPs were uncomfortable with this situation and consequently aimed to involve men more in the dec beginning. Some GPs would talk to patients after PSA screening if it was abnormal but not before; i.e. they would take either a you wish approach before testing, and provide counselling if needed after testing. These GPs perceived some men a seeing a GP at all, so thought it important to be seen to do a test because it was 'something' proactive for them whil rather than simply talking.
48 49 50 51 52 53	

1	
co 2 sultation (GP short of time)	Some GPs who preferred an <i>Analyse and choose</i> approach engaged in less detailed discussion with patients about I
3	when they were short of time. They described selecting out the information to include in discussions with men wh
4	 poor, more in line with the <i>Be Screened</i> or <i>Do not be screened</i> approaches. Some GPs said it is often simply impractical to provide full information and support patients to develop detailed ep
5	understanding at each appointment so on occasions they 'just haven't had time to give a full spiel so I order it and I
6	discussion later with them, if it's positive' (AGP13).
- <i>/</i> - 8	RELATIONAL FACTORSpertaining to patient and/or GP
hat the patient 'starting point' in	Some GPs who usually favoured Analyse and choose, reverted to a Be Screened or Do not be screened approach whe
nformation was low and it would be	was difficult, 'If I had a patient who is extremely unintelligent and I tried to explain it and I didn't seem to be getting t
derstand PSA screening	I felt it was in his best interests, I might go ahead and do the test [or not do the test] anyway' (AGP29)
12	• Some GPs tailored the content accordingly; 'it really depends on the population you're dealing with what you perc
13	capable of understanding' (AGP31); 'You've got to target it at the level of the patient basically' (AGP4).
to be anxious, and so not receptive to	• 'If a man thinks PSA is just a blood test, then I mentally go oh dear, we need to go through this in more detail' (AGP4).
15	• Sometimes GPs provided minimal information to manage anticipated patient anxiety; 'if you put too much information theremost of it doesn't go inthere's too much information'it's not possible for people to take that stuff in, they do
16	(AGP7).
17	In such cases, GPs who would usually communicate in <i>Analyse and let choose</i> mode, acted in what they saw as their
18	interests' (toward <i>Be screened</i> or <i>Do not be screened</i>), which could involve no communication, or being selective w
19	they shared.
hatche patient was 'very switched	• GPs were often more inclined to take the option of As you wish in situations involving well-informed men, regardle
hemework'	practice.
22	• Alternatively, GPs might take an Analyse and choose approach and tailor content accordingly; 'it really depends on t
23	you're dealing with what you perceive they are capable of understanding' (AGP31); 'You've got to target it at the le
	basically' (AGP4).
tory of screening 25	• Some GPs who would prefer the <i>Analyse and choose</i> approach said they 'may not give a full spiel' (AGP13) to men w
nt 26 the past or has discussed	screened before and 'often do it [discuss] a little more quickly, because it is clear that they remember it from the year are men who made the decision last year to have the test done, then they are often going to make the same decision the
pr ⊋7 iously, GP knows patient's	quicker conversation, but it's not a non-conversation. And it depends on the patient and how well I know them' (AGP3
or 26 P knows patient has been	situations, GPs tended to shift to an interaction more like one of the other three approaches.
29	Some GPs were more likely to initiate screening with men who had had PSA screening with them in the past or had
30	tests, because 'generally a lot of my patients by now have had the spiel so many times that they often will, come in an
31	my yearly prostate test' (AGP29).
32	RELATIONAL FACTORSpertaining to service characteristics
attent of another GP, and patient	• Sometimes GPs who preferred an <i>Analyse and choose</i> approach were consulted by patients who were routinely test in this situation, the GP would assume that the man had beautiful the talk before. They remanded to this situation in
34	In this situation, the GP would assume that the man had heard the talk before. They responded to this situation in Some GPs shifted to either the <i>Be screened</i> or <i>As you wish</i> approach and ordered PSA tests without discus
35	man, reasoning that the discussion could be revisited if the PSA was abnormal.
36	o Some GPs maintained <i>Analyse and let choose</i> mode and actively engaged patients in a discussion, because
37	what men had heard from previous GPs. This was sometimes with a view to changing the patient's mind:
38	create permission and faith for me to open the discussion up again, rather than just keep redoing the test' (A
39	• Some GPs found this position incredibly challenging if they preferred not to test (i.e. Do not be screened); 'because'
40	the patient's expectationsyou've got to decide whether you just go with the flowor you sit down and ascertain wha
41	negotiating is. Some of them are just locked into it and it's too late' (AGP23).
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Basic minimum

- 1. False positive PSA test results can occur.
- 2. False negative PSA test results and false negative biopsies of the prostate can occur.
- 3. Nobody knows whether regular PSA screening will reduce the number of deaths from prostate cancer.

Conversation

- 1. The PSA test is a blood test for prostate cancer.
- 2. Done together, the digital rectal examination and the PSA test can screen for prostate cancer.
- 3. The PSA screening test can detect prostate cancer sooner than the digital rectal examination
- 4. An elevated PSA test result may lead to other tests to see whether prostate cancer is present.
- 5. The risk of getting prostate cancer is higher in a man who is older, has a family history of prostate cancer, or is African American.
- 6. Prostate cancer may grow slowly and not cause any symptoms. That is why prostate cancer may not kill older men. They may outlive this cancer and die from something else.
- 7. A man over age 70 is less likely to die from prostate cancer even though he is at higher risk to have it.

Brochure

- 1. The PSA screening test is controversial.
- 2. There are advantages and disadvantages to taking the PSA test. One disadvantage is that a man could end up worrying about what an elevated PSA test result means.
- 3. Done together, the PSA and DRE are most appropriate for men who have more than 10 years left to live.
- A man with early prostate cancer can choose watchful waiting, radical prostatectomy, or radiation therapy.
- 5. There are side effects from prostate cancer treatment such as impotence, incontinence, narrowing of the urethra (strictures), trouble urinating, and rectal scarring.
- 6. Nobody knows whether treating prostate cancer early is helpful or whether one treatment is better than another.
- 7. Although a man thinking about taking the PSA test can consult a doctor, he should make the final decision himself.

Chan et al. identified a core set of key facts that clinicians should include in an 'ideal' discussion about PSA screening

149x124mm (300 x 300 DPI)

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on
			Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with			
participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of	7	What did the participants know about the researcher? e.g. personal	
the interviewer		goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator?	
		e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design	1		*
Theoretical framework			
Methodological orientation	9	What methodological orientation was stated to underpin the study? e.g.	
and Theory		grounded theory, discourse analysis, ethnography, phenomenology,	
		content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience,	
		consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail,	
		email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-	15	Was anyone else present besides the participants and researchers?	
participants			
Description of sample	16	What are the important characteristics of the sample? e.g. demographic	
		data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot	
		tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or only - http://bmjopen.bmj.com/site/about/guidelines.xhtml	

Topic	Item No.	Guide Questions/Description	Reported on	
			Page No.	
		correction?		
Domain 3: analysis and				
findings				
Data analysis				
Number of data coders	24	How many data coders coded the data?		
Description of the coding	25	Did authors provide a description of the coding tree?		
tree				
Derivation of themes	26	Were themes identified in advance or derived from the data?		
Software	27	What software, if applicable, was used to manage the data?		
Participant checking	28	Did participants provide feedback on the findings?		
Reporting				
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings?		
		Was each quotation identified? e.g. participant number		
Data and findings consistent	30	Was there consistency between the data presented and the findings?		
Clarity of major themes	31	Were major themes clearly presented in the findings?		
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?		

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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BMJ Open

Primary goals, information-giving and men's understanding: a qualitative study of Australian and UK doctors' varied communication about PSA screening

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SCHOLARONE™ Manuscripts Primary goals, information-giving and men's understanding: a qualitative study of Australian and UK doctors' varied communication about PSA screening

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Abstract

Objectives:

- To characterise variation in general practitioners' (GPs') accounts of communicating with men about prostate cancer screening using the PSA test;
- 2. To characterise GPs' reasons for communicating as they do; and
- 3. To explain why and under what conditions GP communication approaches vary.

Study design and setting: A grounded theory study. We interviewed 69 GPs consulting in primary care practices in Australia (n=40) and the United Kingdom (n=29).

Results: GPs explained their communication practices in relation to their primary goals. In Australia, three different communication goals were reported: to encourage asymptomatic men to either have a PSA test, or not test, or alternatively, to support men to make their own decision. As well as having different primary goals, GPs aimed to provide different information (from comprehensive to strongly filtered) and to support men to develop different kinds of understanding, from population-level to 'gist' understanding. Taking into account these three dimensions (goals, information, understanding), and building on Entwistle et al.'s (2008) Consider an Offer framework, we derived four overarching approaches to communication: Be screened, Do not be screened, Analyse and choose, and As you wish. We also describe ways in which situational and relational factors influenced GPs' preferred communication approach.

Conclusion: GPs' reported approach to communicating about prostate cancer screening varies according to three dimensions—their primary goal, information provision preference, and understanding sought—and in response to specific practice situations. If GP communication about PSA screening is to become more standardised in Australia, it is likely that each of these dimensions will require attention in policy and practice support interventions.

Strengths and limitations of this study

- Qualitative methodology is well-suited to investigating complex multifaceted processes, like communicating about PSA screening from the perspective of clinicians, and preserves important contextual information relating to the process.
- Data were derived from a large, rigorously derived sample of GPs from different practice
 types and locations, and in two countries. The four approaches identified in this study may
 be applicable to a wide range of practice settings.
- It is possible that those GPs who did not participate were in some way different to those who did (that is, that these data are subject to selection bias), however the diversity in our respondents suggests that it is very unlikely that our sample was biased towards a particular view of PSA screening or corresponding communication style.
- As this is a qualitative study, we cannot infer prevalence of the four reported approaches;
 the results of this study could be extended into quantitative survey research with whole
 populations of GPs to test prevalence.
- Public and patient perspectives were not included in this study; additional qualitative
 research might explore their experiences of communicating with clinicians about prostate
 screening, to further inform policy and practice.

Introduction

Worldwide, many men undergo regular prostate-specific antigen (PSA) screening for prostate cancer risk in primary care. We will use *PSA screening* to refer to PSA testing in ostensibly healthy men who are not considered to be at high risk of prostate cancer for their age; this contrasts with PSA testing in men who have a diagnosis of prostate cancer or are experiencing acute symptoms that may suggest prostate disease. Although the value of the PSA test as a screening tool is scientifically contentious, the public perception of prostate screening is reportedly positive, including an inflated sense of the benefits and underestimation of the harms (1). Access to a PSA test is often via General Practitioners (GPs). The large number of men screened in some countries, and the extent of public misperception and scientific contention, make the communication between men and their GPs about prostate cancer screening especially important.

Communicating about screening is difficult. In-depth discussions about cancer screening can be complex, and may involve multiple statistical concepts, such as test sensitivity and specificity, and absolute and relative risk reduction figures from trial-based evidence. Chan et al. identified over 20 specific informational items that experts and patients identified for inclusion in an 'ideal' discussion about prostate screening (2). The authors synthesised the items into a core set of key facts that clinicians should provide about PSA screening to their patients (Figure 1, developed by KP), however we note that even some of these items are contentious or inconsistent with the various national guidelines that we will discuss in the next section.

Insert Figure 1 about here

Proposed communication standards for PSA screening discussions are reportedly challenging to implement in clinical practice e.g. (3-5). PSA tests are often ordered in the absence of any discussion; in the US, men report being unaware of being screened (6), not being asked for their screening preferences, and undergoing PSA testing without first discussing it with their doctor (7). Clinicians report offering screening without prior counselling (8). A survey of US physicians

reported 20% acknowledged ordering PSA without telling patients (9). This can be for various reasons (10). Volk et al. surveyed US physicians and found that those physicians who reported ordering PSA tests without discussion were more likely to believe that patients wanted to be screened and that education is not needed. This was in contrast to those physicians who engaged patients in pre-screening discussion because they believed patients should know about the lack of evidence supporting screening (11). Physician beliefs about the limitations of the scientific evidence for PSA screening, the questionable utility of the PSA test, and ethical concerns regarding patient autonomy have also been identified as influencing the likelihood of discussions in US studies (10, 12). Physician beliefs can shape the content of discussions; in a UK study, the strong personal views of clinicians against the value of PSA screening were reportedly clearly portrayed in their presentation of information about prostate cancer screening (13).

In addition to this work on physician knowledge, values and attitudes, some researchers have studied patient and practice factors that may facilitate or preclude discussions about prostate cancer screening. For example, in one study US physicians were less likely to discuss screening if a patient had already made a decision about screening, or was perceived to have limited ability to understand the information (10). Other studies have reported on factors affecting the quality of discussions, including a lack of time and the complexity of the topic (9).

Clinicians have cited clinical guidelines and scientific evidence about prostate cancer screening as factors guiding their practice e.g. (13). However this professional guidance varies widely, which may partly explain the observed variation in practice. Table 1 outlines the recommendations of key professional organisations in relation to communicating about prostate cancer screening, illustrating the main points of difference. "Informing" men about the benefits and harms of PSA screening is universally recommended; and use of decision support tools is recommended by half of the professional organisations. Only four of the ten guidelines advise whether GPs should raise the topic of PSA screening with men who do not ask about it in routine consultations. Medico-legal issues are referred to in only one, Australian, guideline. In practice,

clinical guidelines may not always help GPs to decide how and what to communicate about PSA screening (14).

Insert Table 1 about here

Entwistle et al. characterised the two main ways that health care organisations communicate with the public about screening – *Be screened* and *Analyse and choose* – and proposed an alternative approach to communicating about screening, which they termed *Consider an offer* (15). The *Consider an offer* approach suggests health care providers should support people to assess an offer for screening, with a recognition that people may reasonably decline such offers. *Consider an offer* guides clinicians and patients to consider the source of screening recommendations and professional guidance. We return to the *Consider an offer* approach in the Discussion.

This study draws on a larger body of work investigating clinician's approaches to, and reasoning about, PSA screening in Australian and UK general practice. Despite similar levels of prostate cancer mortality, both PSA screening and prostate cancer incidence are lower in the UK than in Australia (16-19). Previous analyses from this study have illuminated systemic variation between the two jurisdictions, including in payment models, the history of PSA screening policy, screening culture, and referral patterns (14). The authors have also published earlier findings from the empirical work about how clinicians manage the potential for overdiagnosis (20) and their responses to uncertainty in relation to prostate screening (21). Table 2 summarises our previous findings regarding differences in PSA screening in the two jurisdictions. Note that prostate cancer screening is not recommended in either location.

Insert Table 2 about here.

In the light of our prior findings on variation between the Australian and UK contexts, we set out to better understand GP communication practices in particular. The larger program of study examined the role of values, ethics, context, and evidence in cancer screening policy and practice. In this paper we present an analysis of how GPs in Australia and the United Kingdom

explain their approach to communication with men about prostate cancer screening. We asked the following research questions, in respect of both settings:

- 1. How do GPs describe their communication with men about prostate cancer screening?
- 2. What are the reasons given by GPs for communicating with men as they do?
- 3. Why and under what conditions do GPs communication approaches vary?

Methods

Ethics approval

Study procedures were approved by the Cancer Institute New South Wales and the University of Sydney Human Research Ethics Committee [#15245]. GPs had an opportunity to discuss the study with KP prior to participation; all GPs provided informed written consent to participate and were compensated AUD \$100 for their time. Participation was voluntary, participants could withdraw at any time, and confidentiality was protected. All responses were anonymised before analysis and potentially identifying information removed.

Design

We applied the well-established, systematic qualitative research methodology of grounded theory (22). Grounded theory is a method of conducting qualitative research that focuses on creating conceptual frameworks or theories through building inductive analysis from the data. All study authors have been formally trained in qualitative research methods; SC has particular expertise in grounded theory methodology.

Participants and Setting

We identified clinicians working in primary care practices as being in the best position to provide insight on our research questions, and most likely to face the question of PSA screening as part of their everyday practice. We purposively recruited a sample of GPs first in the Australian health care setting, and later in the United Kingdom (England, Scotland, and Wales), as our study evolved. Sampling for the broader study was initially driven by existing quantitative evidence on characteristics of GPs, patients, and practice contexts associated with higher or

lower PSA screening rates. We aimed to recruit a set of GPs likely to have diverse practices. See Pickles et al. (14) for a detailed description of the recruitment process.

In Australia we advertised in newsletters and email lists of GP organisations, in mass and social media, medical journals, we phoned practice managers and via email and flyers distributed by rural GP organisations. In the UK, academic colleagues distributed an invitation through their professional networks, we advertised to members of the Royal College of General Practitioners (RCGP), primary health care departments, university academic departments, and general practice and research via mail lists, and in organisational newsletters including the Society for Academic Primary Care (SAPC) and RCGP Scotland's eBulletin. GPs were invited to contact KP if they were interested and willing to participate. An information sheet outlining the research project was emailed to all respondents. All GPs who expressed interest in participating were included.

Overall, 69 GPs participated in this study, 40 GPs in Australia and 29 GPs in the UK. 44/69 of the GPs were male. The GPs ranged in clinical experience, working from 1-40 years in general practice, and were located in both metropolitan (n=32/69) and regional/rural (n=37/69) clinics, with varied patient populations.

Data collection

The field work for the prostate cancer element of this study was conducted by KP, a public health researcher, as part of a PhD degree. KP had no immediate personal or professional experience with prostate cancer or PSA screening.

We generated data via in-depth semi-structured interviews. An interview guide was prepared to provide general direction and an overview of potential question routes. The interview guide covered a broad range of topics, including GPs' recent clinical encounters involving PSA screening decisions, communicating information about the PSA test to patients; screening pathways; and overdiagnosis of prostate cancer. Example questions asked about communication included:

- Describe a recent consultation with an asymptomatic man involving the PSA test...Can
 you take me right back to the beginning and tell me as much as you can about the
 consultation. Who initiated the conversation about the PSA test?
- Should men be informed about overdiagnosis, false positives before having a PSA test?
- How well do you think men understand PSA screening?

The schedule was reviewed and modified between interviews based on the developing analysis to enrich the data available to answer our research questions. All GPs were asked to think back to their most recent consultation involving a discussion about PSA screening or to describe a typical consultation where the topic was raised.

Interviews took place between March 2013 and June 2014 (Australian GPs) and between September and December 2014 (UK GPs). We continued to interview GPs until we judged we had reached theoretical saturation; that is, the point at which gathering more data ceases to yield any further insights about the emerging grounded theory. All interviews were conducted by KP, primarily by telephone or Skype, and ranged in duration from 18 to 70 minutes. With GP permission, the interviews were audio-recorded and transcribed verbatim by a professional transcribing service to produce data for analysis. Transcripts were not returned to participants for comment; all participants will receive a written summary of the research findings on study completion.

Data coding and analysis

The analysis was led by KP, who coded the transcripts. A subset of transcripts was read and coded by three authors independently to ensure interpretive rigor. We coded to capture the range of variation in the GP-reported discussions about PSA screening and for conditions that could explain that variation. Codes were kept as similar to the data as possible to preserve context and to ensure that all concepts derived directly from the data. Codes were compared and discussed to inform the development of the central concepts in the study. KP wrote detailed

memos during data collection and analysis which were reviewed and discussed by the authors in analysis meetings.

Results

We observed considerable diversity in the ways that GPs described their communication about prostate cancer screening. Although the majority of variation occurred among Australian GPs, we also report on data from the UK because this helps illuminate the contrasting complexity of the Australian data, including the role of local context.

We first explain how Australian GPs varied in their descriptions of their communication. In the second section, we consider important ways in which UK and Australian GPs were similar and different.

<u>Australian GPs' accounts of communicating with men about prostate cancer screening</u>

Australian GPs' accounts varied greatly in how they introduced conversations about PSA screening with men, how screening discussions were framed, and their perceived informational obligations.

Screening men with little or no prior communication

A minority of interviewees reported ordering PSA tests for asymptomatic men with little or no prior communication with the patient. GPs were categorised as non-communicative if they reported (1) ordering PSA tests without explaining that to their patient, (2) ordering PSA tests at patient request with no further discussion, or (3) explaining PSA screening only after a positive PSA test result. We encountered occasional practices from which asymptomatic men were mailed pathology forms for a PSA test via practice recall systems, bypassing a GP consultation and opportunity for discussion.

Several possible justifications were provided by non-communicative GPs:

Some GPs reasoned that because the information about PSA screening was 'confusing'
 'complicated' and potentially contradictory, it should not be provided.

- Some GPs said their role was to ensure that men could be screened if they wanted, 'I see doctors purely as enablers, of what people want...If you don't want to read about it [the test], then fine; I'll just order one for you' (AGP17).
- Some GPs considered it 'up to each patient to be informed appropriately' (AGP14); if a
 man requested a PSA they would order a test assuming that man felt sufficiently
 informed from other sources.
- Some GPs considered it unnecessary to provide information unless the man received a cancer diagnosis, 'I don't think they need all that information at the level of PSA testing. I think, that once you've got your cancer diagnosis, you can talk about what you want to do with that then' (AGP26).
- Some GPs did not appear to have a complete understanding of the epidemiological data, for example, 'someone was saying that a certain number of people had to have radiation and surgery and have impotence and incontinence, for one person's life to be saved. I mean I don't know how you get those figures' (AGP2).

These were, however, minority views. We focus in what follows on the majority of GPs who *did* communicate with men in some way about PSA screening.

Communicating with men, with variation on three key dimensions

We identified three dimensions central to GP discussions with men about PSA screening:

- 1. The GPs' primary communication goal. Some GPs had the goal of convincing the patient to screen, some had the goal of convincing the patient not to screen, and some had the goal of supporting decisions or facilitating patient choice;
- 2. The type of information the GP provided; and
- 3. The type of patient understanding the GP sought to achieve.

It appeared that Dimension 1 was dominant; GPs communicated in accordance with their preferred goal or outcome of the communication. In most cases, the GP's positioning on dimensions 2 and 3 was grounded in whether the GP felt strongly that patients should be

screened or not, and the degree to which they directed men towards that preference. Below we explain these three dimensions, and GPs' reasoning about them.

Dimension 1. GP's primary communication goal

Some GPs aimed to convince men either to agree to be screened, or to agree not to be screened. These GPs had strong beliefs regarding whether or not PSA screening should occur routinely, and wanted patients to follow their advice, their 'guide...down the path' towards what they 'thought was best' (AGP29). GPs acknowledged 'bias will creep into that' (AGP29); 'you can't help yourself but...what you believe in is the way you push the consultation' (AGP18). However this approach was justified by beliefs that, '...you can only do what you think is best for the patient' (AGP29) and 'a lot of people do want to be told what to do...doctors are their reference point' (AGP31). GPs recognised that men sometimes chose not to take the advised pathway, for example, 'there are times when it wouldn't matter what you said to a patient they're still determined to have the test' (AGP18).

An alternative communication goal was to support men to make decisions about screening consistent with their own values and preferences. GPs with this goal aimed to facilitate an informed decision making process and were determined to provide information to all men 'to make up their own mind' (AGP16), because 'with the PSA test, I can't so easily say to myself, well, it's in your best interests so I don't need to inform you properly' (UKGP9). GPs with this goal reasoned that a man 'should be empowered to know everything' (UKGP28); 'should have the right and want to be able to make that decision for themselves about whether they have the test or not' (AGP5).

Dimension 2. GPs' reported information provision

Because GPs had different goals in communicating, they provided different information, in both quality and quantity.

Some GPs claimed to provide men with 'complete' and 'unbiased' information, because they considered it their 'ethical obligation' as a health professional to do so; the patient, in this view, had a 'right' to be fully informed, so GPs should '[put] all the information on the table' (AGP31); 'I'm very keen that people are well-informed about really what it means if they are to undertake a PSA rather than just simply agreeing to what their idea might be' (UKGP23). This sometimes

extended to teaching patients how to locate and interpret information for themselves. Informing patients was described by some GPs as serving a self-protective legal purpose, *T've informed the patient, the patient made his own decision, so he's got to then accept the consequences'* (AGP19).

In contrast to GPs who sought to provide comprehensive information, other GPs filtered information to 'actually tell them [patients] what counts the most' (AGP4). Here GPs aimed to explain their own best judgment about the evidence, framing the evidence according to the GP's opinion regarding the value of PSA screening. This often took the shape of a personal recommendation either to have a PSA test or not. One GP, for example, said '[patients] don't have that knowledge so you sort of, give an explanation why it needs to be done' (AGP35); another, in contrast, thought 'my discussing it has probably been biased towards not getting it done' (AGP16). Some GPs considered such advising to be best practice, because information provision alone was not enough to help men decide what to do. For example, one GP who favoured PSA screening reasoned, 'If they really don't know what to do then [after receiving information], any doctor would be a fool not to say look, get it investigated because, the most stupid thing anyone could do is say oh don't bother about it...that's just a total recipe for disaster' (AGP31).

Dimension 3. GPs' reported ambitions for men's understanding

All GPs aimed to support the development of patient understanding. However there were two different conceptions of what constituted appropriate understanding of the information presented and available options:

1) Sometimes GPs aimed to assist men to develop detailed *population-level understanding* of the evidence. They wanted men to understand all aspects of the information provided and described checking understanding, identifying gaps in patient knowledge, and clarifying misunderstandings, because 'I don't think their pre-existing understanding of the test is very good at all in most cases' (UKGP21). Some of these GPs reported feeling personally and professionally responsible for presenting the 'right amount' and 'right level' of information for individual patients, '[achieving understanding is] really the doctor's job, and our skill in trying to explain all that complicated evidence, as best as we can' (AGP19). Some GPs commented they hoped men

understood the detail of the evidence, otherwise it indicated they as a GP had done a 'bad job of explaining it' (AGP6), however they also explained 'it's a very difficult thing to formally confirm that they understand the implications of having the test done without kind of interrogating them' (UKGP1).

2) Alternatively, GPs might aim for men to develop overall 'gist' understanding. GPs committed to 'gist' understanding were satisfied if their patient had a less complete grasp of the intricacies of the evidence base, as long as they had an overall understanding of what the GP perceived to be core issues; 'I feel like as long as they can understand that basic concept [in this instance, that PSA is not a perfect test] ...then I feel like it's okay to still do the testing, even if they don't understand all the detail...I feel like that's a reasonable level of understanding, I don't feel like people need to have an absolutely thorough kind of understanding' (AGP5). Those GPs who thought 'gist' understanding was acceptable thought it was reasonable for men to trust their doctor to advise them appropriately.

Relationship between the dimensions

When taking account of the three dimensions along which GPs varied, we identified four overarching approaches to communication: (1 & 2) *Be Screened* and *Do not be screened* (GPs who guided men towards screening or not screening); (3) *Analyse and choose* (GPs who aimed to ensure men made their own independent, informed decision, based on a detailed population-level understanding); (4) *As you wish* (GPs who simply facilitated the man's stated preference to be screened or not screened). Two of these terms (*Be Screened* and *Analyse and choose*) align with Entwistle et al.'s characterisation of communication approaches (15), as outlined in the introduction. Each GP we interviewed had a general preference to employ one of these four approaches in their everyday communication about PSA screening. In Table 3 we present an integrated illustration of the characteristics of each approach, ordered according to the 3 key dimensions evident in the GP accounts.

Insert Table 3 about here.

Be Screened or Do not be screened interactions. If GPs had a strong preference that men should either be screened or avoid screening, they communicated in a directive way, oriented to encouraging the man either to screen or avoid screening respectively. This included offering personal judgment about the value – or harms – of PSA screening or framing the information they provided towards or away from screening. Some GPs gave a recommendation without offering men any further information. In Be screened and Do not be screened interactions, GPs considered it sufficient that men developed gist understanding of the information provided, because they thought it was reasonable for men to trust their doctor to advise them appropriately. These GPs strongly believed either that men should be screened routinely, or that they should not be screened at all, and they wanted patients to follow their advice.

Analyse and choose interactions. If GPs aimed to support men to make their own decisions, consistent with the man's personal preferences (i.e. a patient-directed decision), then they were not directive in their communication. In these interactions, GPs aimed to provide a comprehensive and impartial summary of the best available evidence; their goal was to ensure that men developed a detailed population-level understanding of their options in order to make an informed decision. They saw this as a neutral, educative role. For some, this approach was protective against potential medico-legal threats. GPs using this approach may personally favour either screening or not screening, but their primary commitment was to support the man's decision, regardless of their own professional beliefs about screening.

As you wish interactions. Sometimes GPs acted on patient wishes to be screened or not screened without questioning. In these interactions GPs did not attempt to direct men in any particular direction, and often provided little information, ensuring that the man understood PSA screening was not a priority. In some cases, GPs perceived men to have already made a screening choice based on personal preference or gist understanding. These consultations typically involved men with an already-established screening preference, mostly for screening; the GP simply acted in line with the man's instructions.

How GPs negotiate communicating within specific contexts

Many Australian GPs reported discussing PSA screening with men often, so had a prepared basic 'spiel'; as one reported, 'the PSA is such a common question that you get asked and you just have to have some idea in your head what you're going to say when they come in' (AGP18). This spiel could be tailored to specific contexts as necessary. GPs' interviews indicated that they tended to have a preferred approach for most PSA interactions (to guide patient toward screening or not screening, to support men to make their own decision, or to act in accordance with the man's expressed preference), or that they had maintained a particular communication style over time. However we identified eleven situational and relational factors (see Table 4) that GPs described as temporarily shifting their usual or preferred communication goals and processes. These factors predominantly arose from specific circumstances of individual consultations. GPs described modifying their provision of information and/or advice, depending on the eleven factors described in Table 4.

Insert Table 4 about here

GPs also shifted between the four communication approaches more readily when they were presented with complex cases; producing more fluid, responsive, and sometimes 'quite inconsistent' (AGP16) conversations. Many GPs did have a primary goal when communicating (to encourage or discourage screening, or to support the man to make his own decisions) but these could change in different situations. Also, some men did not take the advised pathway – either toward screening or not screening, or some men preferred the GP to direct the decision, not wanting to engage with information or to make their own decision.

Comparison of communication approaches in Australia and the UK

UK GPs generally did not communicate about PSA screening unless men asked about it, so they often neither communicated about it as a screening test, nor ordered it. When men asked for a PSA test, information provision was central to consultations in the UK context, and most UK GPs

commonly practiced according to the *Analyse and choose* or *Do not be screened* approaches. Few UK GPs described adjusting their conversations about PSA screening with patients.

The reported consistency of PSA communication practices in the UK contrasted strongly with the significant variation reported in the Australian context (Tables 3 and 4). The contextual factors considered in Table 4 were uncommon in UK GPs' accounts, due to fewer men requesting and fewer GPs suggesting prostate screening. UK GPs mostly reported giving the same standard information leaflet to all men who expressed interest in PSA screening, regardless of their personal circumstances. Many GPs practicing in Australia tended to filter information, and commonly practiced according to the *Be Screened* approach, but no UK GPs reported using this approach.

We identified different versions of the *Do not be screened* approach adopted by Australian and UK GPs. For the Australian GPs, this approach took the form of a personal recommendation against screening, directed by the GP and according to their personal – negative – perspective of PSA screening. For UK GPs, the *Do not be screened* approach also involved the GP recommending that the man should not be screened. However UK GPs explained this as enactment of a collective standard of care recommended and issued by the UK National Health Service irrespective of their own personal preferences for or against screening.

Discussion

This analysis suggests that GPs' primary communication goals are a central component of consultations about prostate screening. Four distinct communication approaches – *Be Screened*, *Do not be screened*, *Analyse and choose*, and *As you wish* – were identifiable from GPs' accounts of their preferred practice.

The terms *Be Screened* and *Analyse and Choose* align with Entwistle et al.'s Consider an Offer framework. We identified two additional ways of communicating unique to our empirical data, which we labeled *Do Not Be Screened*, and *As you wish*. The need for inclusion of a *Do not be Screened* element is likely a product of the Australian context where the PSA test is available and widely promoted for screening purposes in the media, despite the majority of relevant public

health and health professional groups recommending against routine screening of asymptomatic men. This meant Australian GPs were regularly consulted by men expecting to be screened, and some reported feeling obligated to actively direct men away from wanting a PSA test for that purpose.

The *As you wish* category is also likely to be, in part, a reflection of the somewhat market-driven Australian health care system. *As you wish* interactions occurred when GPs' believed men had already made up their minds about their preferred choice, and could not be swayed by information presented by the GP. This led GPs to implement the man's choice and order the test, despite the lack of an evidence base to support that decision. There was no evidence of *As you wish* interactions in the UK data. As we previously reported (14), in the UK there is strong guidance to GPs to practice in a particular way. GPs are expected to steward limited NHS resources, and the PSA test is not publicly promoted to the same extent, limiting consumer expectations for screening. All of these are conceivable explanations for why *As you wish* interactions were less commonly reported in UK interviews.

The main issues raised by this analysis

The four variants raise important questions about patient-centered care, consumer demand, and the role of the health professional. It is well established in the literature that both patients and clinicians are rarely entirely rational, and may not necessarily know what is in the patient's best interest, particularly when faced with scientific uncertainty e.g. (23, 24). Humans tend, for example, to become sensitised to worst-case scenarios and disregard objective risk probabilities; this makes us vulnerable to pursuing, recommending, or accepting potentially harmful treatments (25). If this is so, an *As you wish* approach could mean patients are more exposed to increased harms, and that leaving patients to make decisions about their health care needs without professional guidance is potentially maleficent, or at least negligent. This problem is further complicated by the wide availability of possibly misleading information, provided by sources that have an interest in inflating perceptions of cancer risk. Some authors highlight that increased patient involvement in decision making has potential for negative social consequences

such as increasing patient demand for unproven services (26). Cribb and Entwistle reasonably argue that in some circumstances it may be ethically legitimate for health professionals to question and even influence the preferences of patients for these reasons (27).

Most current recommendations encourage GPs to discuss the benefits and harms of prostate cancer screening with patients. However, there may be considerable variation in what patients want and expect from GPs prior to making a decision about PSA screening. Degeling et al. ran three community juries on the topic of how GPs should communicate about PSA screening. Juries heard extensive expert evidence about PSA screening, consent and general practice. Two juries of general citizens (i.e. mixed gender and age) concluded that GPs should ensure men have enough knowledge to make their own decision. One jury of only men of PSA screening age concluded that men should be able to trust their GP (or a specialist) to provide just enough information at just the right time, expressed concern about the potential for information overload, and thought the degree of patient involvement depended on the patient (28). This suggests that citizens who are (atypically) well-informed about the benefits and harms of prostate cancer screening may take different views and have different expectations on how GPs should communicate about PSA screening. If this is the case, it may be appropriate for GPs to have at least a range of communication strategies available, to suit the needs of different patients. Men eligible for, or already receiving, PSA screening, may well prefer for GPs to direct the decision (Be screened or Do not be screened approaches) to avoid uncertainty. However men's preferences are arguably an insufficient guide; other considerations, including clinical practice guidelines, medical law and clinical ethics requirements, are relevant to determining what GPs should do.

A large component of this analysis is about awareness of and sensitivity to context and the importance of interpersonal relations and their influence on communication practice (see Table 4). Some of the GPs' communication decisions, based on situational or individual factors, were easily justified, because the situation presented was either clinically relevant (e.g. family history, older age), or professionally justified (e.g. low literate patient, patient request). While most

guidelines advising on PSA screening suggest informed or shared decision making, they do not consider what may be a 'best' approach to situations involving the many local factors that GPs' face in day to day practice, including relational factors, implicated in screening decisions (and the complexities of general practice). We identified a subtle web of relational issues that influenced GPs to move between communication options and particular types of decision pathways. These included managing colleague associations (what are GPs to do about patients who have come from a pro-screening GP to a GP who does not support PSA screening?), managing business, including patient lists (patient request, time pressures), and maintaining patient trust. These issues made the decision making process particularly complicated, and in addition to vague guidance on such matters, perhaps account for why many GPs appeared to have multiple, dynamic approaches. Accounting for relational variables as identified in this study can facilitate nuanced assessment of the different types of support clinicians might offer people who may struggle with particular decisions (29), and allows scope for professional expertise: the 'art' of medicine.

Implications for policy and practice

There are variable approaches to communication about PSA screening, some of which may be considered better than others. Guidance about communication - not just about the PSA test itself, but also about how best to facilitate the decision – may be useful; we suggest there is a need for further higher level professional discussions about what the primary goals of GPs should be when communicating about PSA screening. Coming to an explicit agreement on what that purpose should be may assist in improving communication and providing clearer guidance for GPs working in the Australian context. For instance, one endpoint (that could be evaluated) may be that men can demonstrate they have a sense of their values in relation to the available options, to show evidence of rational, thoughtful, and informed decision making.

Limitations

As this is a qualitative study, we cannot infer the prevalence of the reported approaches to communication; the results of this study could be extended into quantitative survey research

with whole populations of GPs to test prevalence. It is also possible that those GPs who did not participate were in some way different to those who did (that is, that these data are subject to selection bias), however the diversity in our respondents suggests that it is very unlikely that our sample was biased towards a particular view of PSA screening or corresponding communication style.

Conclusion

This empirical study produced evidence documenting varied approaches to communication. The reported consistency of PSA communication practices in the UK contrasted strongly with the significant variation reported in the Australian context. In the Australian setting, some flexibility in communication seems justified. Further, because of (a) the large number of men implicated, (b) the known harms of the screening process, and (c) that PSA is not a routine screening program, we argue that PSA screening is a particularly pressing case to necessitate dedicated effort to facilitate conversations that include but go beyond potential harms and benefits with men. This would include encouraging and enabling men who ask for screening to look carefully at why PSA screening is not recommended (to increase awareness of why a *Do not be screened* approach is justified). Assisting GPs to facilitate these conversations with patients should offer the advantage of supporting men's autonomy and reducing harm.

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Transparency: KP affirms that the manuscript is an honest, accurate, and transparent account of the study being reported; no important aspects of the study have been omitted.

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Ethical approval: All study procedures were approved by the Cancer Institute NSW and the University of Sydney Human Research Ethics Committee [#15245]. Each participant gave signed consent prior to the interview.

Data sharing: No additional data available.

Contributorship: KP, SC, and LR conceived the study and were involved in designing the study and developing the methods. SC & LR obtained funding and were CIs on the NHMRC funded project grant; VE was an AI on the project. KP conducted the interviews, had full access to all data in the study, and takes responsibility for the integrity of the data and the accuracy of the data analysis. KP drafted the manuscript. All authors (KP, SC, LR, KM, VE) contributed to the interpretation of the analysis and critically revised the manuscript.

Figure 1.

TITLE: Proposed content for informed consent for PSA screening (Chan et al., 1998, figure developed by KP)

LEGEND: Chan et al. identified a core set of key facts that clinicians should include in an 'ideal' discussion about PSA screening



Table 1. The recommendations of professional organisations in terms of communicating about prostate screening

d in recommendation and		Professional Organisation								
guidance 6	PCFA/CCA1	NHMRC ²	RACGP ³	USANZ4	NICE ⁵	NHS/PHE6	USPSTF7	ACS ⁸	NCI ⁹	Al
o r t whether to raise the if 8 en do not raise it first?			1		✓	1	1			
9 I recommended?	1	1	1		✓					
11 lppgvided?						1				
— 13 nem(d≱d? — 15	✓	1	1	1	✓	1	1	1	✓	
ne fl6 ed? 17			1		✓		1			
om pa nied by a clinician et 3 9	1	\ \				✓	1			
on 20 nied by a patient et 2 4		\ \	1		✓	✓				
reanmend clinician to share craning decision?							1			
o- ½5 al responsibilities?			1							

tate Cancer Foundation of Australia/Cancer Council Australia il Health and Medical Research Council stranan College of General Practitioners

cal **29**ciety of Australia and New Zealand

nal**30**stitute for Health and Care Excellence

⁶NHS/PHE: National Health Service/Public Health England

⁷ USPSTF: United States Preventive Services Task Force

⁸ ACS: American Cancer Society

⁹ NCI: National Cancer Institute of the National Institutes of Health

¹⁰ AUA: American Urological Association

be 🔏 on Making (IDM): The patient is presented with all the information pertinent to making a decision and then assumes final authority for the decision (30). ris🚱 Making (SDM): The patient is provided with all the relevant information and works with the health care provider to reach a decision that reflects the healt ofthe patient (30).

information sheet is a fact sheet summarizing the evidence of benefits, limitations, and associated risks of prostate screening to help clinicians to accurately info

35 aformation sheet is a fact sheet outlining the benefits, limitations, and associated risks of having a PSA test for prostate cancer risk.

Table 2. The organisation and occurrence of PSA screening in Australia and the United Kingdom [summary of findings, details reported in Pickles et al 2016]

advised to offer evidence-based decisional support to men considering whether or not to have a PSA test, including the opportunity to discuss the benefits and harms of PSA screening before making the decision. Screening frequency • GPs reported frequently providing PSA screening within routine consultations. • GPs reported often initiating discussion of PSA screening sto individual standards. • Australian guidance was mixed (see Table 1). The NHMRC has recently issued guidance to Australian GPs to drive greater consistency in practice. Preferred form of information provision Appointment • PSA screening tests were usually advised to offer evidence-based decisional support to men considering whether or not to have a PSA test, including the opportunity to discuss the benefits and harms of PSA screening for prostate cancer be available for asymptomatic men, on the understanding that they have been provided with full and balanced information about the advantages and limitations of the PSA test. GPs reported frequently providing PSA screening discussion of PSA screening, GPs reported dommonly receiving requests for PSA screening. GPs reported often initiating discussion of PSA screening, they also reported that men rarely asked for PSA screening. Government-issued standards for PSA screening and communication processes in clinical settings are in place. Guidance has been distributed to all GPs in England and Wales to assist in the provision of information to men. GPs can choose to follow issued guidance but seem inclined to operate within the bounds of their health system. GPs reported ference or of the making the understanding that they have been provided with full and balanced information asymptomatic men, on the understanding that they have been provided with full and balanced information so the PSA screening was rare in practice. GPs reported that PSA screening was rare in practice. Government-issued standards for PSA screening and communication provision of information to men. GPs can choose to		Australia	United Kingdom
Screening frequency GPs reported frequently providing PSA screening within routine consultations. GPs reported often initiating discussion of PSA screening; GPs reported commonly receiving requests for PSA screening. Guidance for GPs GPs are free to practice according to individual standards. Australian guidance was mixed (see Table 1). The NHMRC has recently issued guidance to Australian GPs to drive greater consistency in practice. Preferred form of information provision PSA screening. GPs reported that PSA screening was rare in practice. UK GPs reported not promoting PSA screening; they also reported that men rarely asked for PSA screening. Government-issued standards for PSA screening and communication processes in clinical settings are in place. Guidance has been distributed to all GPs in England and Wales to assist in the provision of information to men. GPs can choose to follow issued guidance but seem inclined to operate within the bounds of their health system. GPs reported that PSA screening PSA screening; they also reported that men rarely asked for PSA screening. Government-issued standards for PSA screening and communication processes in clinical settings are in place. Guidance has been distributed to all GPs in England and Wales to assist in the provision of information to men. GPs can choose to follow issued guidance but seem inclined to operate within the bounds of their health system. GPs reported relying on a standardized printed information leaflet. This was central to the consultation, sometimes alongside a brief verbal discussion. Information-giving occurred in a separate appointment to PSA screening itself.	screening	advised to offer evidence-based decisional support to men considering whether or not to have a PSA test, including the opportunity to discuss the benefits and harms of PSA screening before making the	conditions. The National Health Service Prostate Cancer Risk Management Programme (PCRMP) has recommended that screening for prostate cancer be available for asymptomatic men, on the understanding that they have been provided with full and balanced information about the advantages and
to individual standards. Australian guidance was mixed (see Table 1). The NHMRC has recently issued guidance to Australian GPs to drive greater consistency in practice. Preferred form of information provision Or GPs reported generally informing men via a verbal discussion of PSA screening. PSA screening tests were usually discussed and ordered in a single appointment. screening and communication processes in clinical settings are in place. Guidance has been distributed to all GPs in England and Wales to assist in the provision of information to men. GPs can choose to follow issued guidance but seem inclined to operate within the bounds of their health system. GPs reported relying on a standardized printed information leaflet. This was central to the consultation, sometimes alongside a brief verbal discussion. PSA screening tests were usually discussed and ordered in a single appointment to PSA screening itself.		PSA screening within routine consultations. GPs reported often initiating discussion of PSA screening; GPs reported commonly receiving requests for PSA screening.	rare in practice. • UK GPs reported not promoting PSA screening; they also reported that men rarely asked for PSA screening.
information provision men via a verbal discussion of PSA screening. PSA screening tests were usually discussed and ordered in a single appointment. PSA screening tests were usually discussed and ordered in a single appointment to PSA screening itself.	Guidance for GPs	to individual standards. • Australian guidance was mixed (see Table 1). The NHMRC has recently issued guidance to Australian GPs to drive greater	screening and communication processes in clinical settings are in place. Guidance has been distributed to all GPs in England and Wales to assist in the provision of information to men. GPs can choose to follow issued guidance but seem inclined to operate within the bounds of their health
structure discussed and ordered in a single separate appointment to PSA screening itself.	information	men via a verbal discussion of PSA	GPs reported relying on a standardized printed information leaflet. This was central to the consultation, sometimes
		discussed and ordered in a single	separate appointment to PSA screening

Table 3. Four GP approaches to communication about PSA screening in clinical interactions

BE SCREENED interactions

GP's primary goal:

- GP strongly believed that the man should be screened
- GP goal is to convince the man to screen

Information provided by GP:

- GP's personal judgment about the value of PSA screening
- GP either tailored information provided to men to encourage men to be screened, or did not provide information (provided only encouragement to be tested)

Type of understanding that GP considered adequate:

Gist understanding of information provided

ANALYSE & CHOOSE interactions

GP's primary goal:

- GP may personally support testing or not testing
- Despite their personal beliefs about testing, GP's goal is to help the man to make his own informed decision

Information provided by GP:

 GP aimed to provide a comprehensive and impartial summary of best available evidence

Type of understanding that GP considered adequate:

 GP goal was to ensure men developed detailed understanding of their options, to make own informed decision

DO NOT BE SCREENED interactions

GP's primary goal:

- GP strongly believed that the man should not be screened
- GP goal is to convince the man not to screen

Information provided by GP:

- GP's personal judgment about the harms/downsides of PSA screening
- GP either tailored information provided to men to discourage screening, or did not provide information (provided only encouragement to avoid testing)

Type of understanding that GP considered adequate:

• Gist understanding of information provided

AS YOU WISH interactions

GP's primary goal:

- GP may or may not have a strong position on the value of PSA screening
- GP's goal is simply to follow the man's expressed preference

Information provided by GP:

GP provided little information

Type of understanding that GP considered adequate:

 Ensuring men understood was not a priority for the GP. In some cases, GP perceived men to have already made a screening choice based on personal preference or gist understanding

Table 4. The effect of situational and relational factors on GPs' approaches to communication in PSA screening interactions, as described by GPs

3	
ouraged particular approaches to t PSA screening, as described by GPs	Examples of how GPs reported modifying their communication
pertaining to patient and/or GP	
def or younger age group (particularly 78 years), or had comorbidities 9 10 11 12 13	 Some GPs paid closer attention to which direction they 'coaxed' patients in these age groups; for example, some we emphasise false positives and the potentially harmful diagnostic pathway to younger men under 50 years (i.e. GP Do not be screened approach). Some GPs who usually communicated in Be Screened mode provided comparatively less detailed information for particularly those with declining memory or those they perceived as being cognitively unable to 'handle the infor 'pick[ing] the details of the intricaciesand a lot briefer [conversation]' (AGP17) Some GPs described defaulting to providing stronger recommendations with elderly men.
story of prostate cancer	• Conversations with men with family history of prostate cancer were described as being slightly different; some G
15 16 17 18	 interactions with these men would be more 'considered' and 'gentle' despite the majority of the men knowing the coming to the doctor. Some GPs who generally communicated in a way to achieve screening (<i>Be screened</i>) or not screening (<i>Do not be so</i> their approach more towards <i>Analyse and choose</i> and <i>As you wish</i> in situations where a family history was implications those determined to be tested and those not wishing to be tested.
ceive a PSA test or was perceived to be	These patients were perceived to have positive preconceptions about PSA screening which pre-empt any GP discrease.
es20 21 22 23 24 25	 Some GPs who would usually communicate with a particular goal in mind (<i>Be screened</i> or <i>Do not be</i> screened) sai conversation counter to the man's beliefs was not a productive conversation because their intentions could not be see it as their right to have it [a PSA test]' (AGP15); 'he was so definite he wanted it' (AGP6). GPs tended to take the approach in these situations, even if this was not their preference. 'I think that what changes in that situation is their determination to have the testing done, most of these men have method before I've said anything, that they're going to be tested, no matter what I say' (AGP8).
inggading out more about screening	 Some GPs reasoned that a man's interest in PSA screening would drive the discussion, 'it tends to be very patient's
27 28 29	 tailored adviceand depends on what I think that they expect and hope to hear and are likely to do' (AGP16). GPs who usually took an As you wish approach, so did not communicate, would in some situations be required to sother three approaches (Be screened, Do not be screened, Analyse and choose) because the man requested information.
30	Some GPs said the discussion would become 'more complicated' the more interested the patient was.
pertaining to service characteristics	
ited access to urology services 33 34 35 36 37 38 39 40 41	 Some GPs were influenced by their access to a Urologist. Although they might prefer to recommend that men Be S be screened, they described instead shifting their approach towards Analyse and choose when based in a rural loca try to explain the test, do a bit more pre-test counselling with the patient when I was in the country, just because I kn be managing the result rather than just sending them onto a Urologist, like it's easy to do in Sydney' (AGP5). GPs des rural locations it is common for GPs to have to manage abnormal PSAs for a longer period before they can access second opinion. Some GPs were uncomfortable with this situation and consequently aimed to involve men more i from the beginning. Some GPs would talk to patients after PSA screening if it was abnormal but not before; i.e. they would take either As you wish approach before testing, and provide counselling if needed after testing. These GPs perceived some m seeing a GP at all, so thought it important to be seen to do a test because it was 'something' proactive for them wh there, rather than simply talking.
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coæsultation (GP short of time) 3 4 5 6	 Some GPs who preferred an <i>Analyse and choose</i> approach engaged in less detailed discussion with patients about when they were short of time. They described selecting out the information to include in discussions with men time poor, more in line with the <i>Be Screened</i> or <i>Do not be screened</i> approaches. Some GPs said it is often simply impractical to provide full information and support patients to develop detailed understanding at each appointment so on occasions they 'just haven't had time to give a full spiel so I order it and discussion later with them, if it's positive' (AGP13).
7 pertaining to patient and/or GP	uiscussion lucer with them, if it's positive (Aut 13).
hat the patient 'starting point' in terms attion was low and it would be difficult PSA screening 12 13 to be anxious, and so not receptive to 15 16 17	 Some GPs who usually favoured Analyse and choose, reverted to a Be Screened or Do not be screened approach we communicating was difficult, 'If I had a patient who is extremely unintelligent and I tried to explain it and I didn't a through to him, and I felt it was in his best interests, I might go ahead and do the test [or not do the test] anyway' (and Some GPs tailored the content accordingly; 'it really depends on the population you're dealing with what you provide of understanding' (AGP31); 'You've got to target it at the level of the patient basically' (AGP4). 'If a man thinks PSA is just a blood test, then I mentally go oh dear, we need to go through this in more detail' (AGP Sometimes GPs provided minimal information to manage anticipated patient anxiety; 'if you put too much information'it's not possible for people to take that stuff in, they (AGP7). In such cases, GPs who would usually communicate in Analyse and let choose mode, acted in what they saw as the
18	interests' (toward Be screened or Do not be screened), which could involve no communication, or being selective
19 hæghe patient was 'very switched on' næyork' 22 23	 GPs were often more inclined to take the option of <i>As you wish</i> in situations involving well-informed men, regard usual practice. Alternatively, GPs might take an <i>Analyse and choose</i> approach and tailor content accordingly; 'it really depends of you're dealing with what you perceive they are capable of understanding' (AGP31); 'You've got to target it at the basically' (AGP4).
124 of screening 25 nt 26 the past or has discussed pr27 iously, GP knows patient's or 26 knows patient has been 29 30 31	 Some GPs who would prefer the Analyse and choose approach said they 'may not give a full spiel' (AGP13) to men screened before and 'often do it [discuss] a little more quickly, because it is clear that they remember it from the year they are men who made the decision last year to have the test done, then they are often going to make the same decit's a quicker conversation, but it's not a non-conversation. And it depends on the patient and how well I know them situations, GPs tended to shift to an interaction more like one of the other three approaches. Some GPs were more likely to initiate screening with men who had had PSA screening with them in the past or lests, because 'generally a lot of my patients by now have had the spiel so many times that they often will, come in for my yearly prostate test' (AGP29).
perpaining to service characteristics	
atignt of another GP, and patient asked 34 35 36 37 38 39 40 41	 Sometimes GPs who preferred an Analyse and choose approach were consulted by patients who were routinely GP. In this situation, the GP would assume that the man had heard the talk before. They responded to this situat Some GPs shifted to either the Be screened or As you wish approach and ordered PSA tests without disc man, reasoning that the discussion could be revisited if the PSA was abnormal. Some GPs maintained Analyse and let choose mode and actively engaged patients in a discussion, because know what men had heard from previous GPs. This was sometimes with a view to changing the patient trying to create permission and faith for me to open the discussion up again, rather than just keep redoing Some GPs found this position incredibly challenging if they preferred not to test (i.e. Do not be screened); 'because the patient's expectationsyou've got to decide whether you just go with the flowor you sit down and ascertain we for negotiating is. Some of them are just locked into it and it's too late' (AGP23).
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Basic minimum

- 1. False positive PSA test results can occur.
- 2. False negative PSA test results and false negative biopsies of the prostate can occur.
- 3. Nobody knows whether regular PSA screening will reduce the number of deaths from prostate cancer.

Conversation

- 1. The PSA test is a blood test for prostate cancer.
- 2. Done together, the digital rectal examination and the PSA test can screen for prostate cancer.
- 3. The PSA screening test can detect prostate cancer sooner than the digital rectal examination
- 4. An elevated PSA test result may lead to other tests to see whether prostate cancer is present.
- 5. The risk of getting prostate cancer is higher in a man who is older, has a family history of prostate cancer, or is African American.
- 6. Prostate cancer may grow slowly and not cause any symptoms. That is why prostate cancer may not kill older men. They may outlive this cancer and die from something else.
- 7. A man over age 70 is less likely to die from prostate cancer even though he is at higher risk to have it.

Brochure

- 1. The PSA screening test is controversial.
- 2. There are advantages and disadvantages to taking the PSA test. One disadvantage is that a man could end up worrying about what an elevated PSA test result means.
- 3. Done together, the PSA and DRE are most appropriate for men who have more than 10 years left to live.
- A man with early prostate cancer can choose watchful waiting, radical prostatectomy, or radiation therapy.
- 5. There are side effects from prostate cancer treatment such as impotence, incontinence, narrowing of the urethra (strictures), trouble urinating, and rectal scarring.
- 6. Nobody knows whether treating prostate cancer early is helpful or whether one treatment is better than another.
- 7. Although a man thinking about taking the PSA test can consult a doctor, he should make the final decision himself.

Chan et al. identified a core set of key facts that clinicians should include in an 'ideal' discussion about PSA screening

149x124mm (300 x 300 DPI)

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on
			Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with			
participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of	7	What did the participants know about the researcher? e.g. personal	
the interviewer		goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator?	
		e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design	1		*
Theoretical framework			
Methodological orientation	9	What methodological orientation was stated to underpin the study? e.g.	
and Theory		grounded theory, discourse analysis, ethnography, phenomenology,	
		content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience,	
		consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail,	
		email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-	15	Was anyone else present besides the participants and researchers?	
participants			
Description of sample	16	What are the important characteristics of the sample? e.g. demographic	
		data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot	
		tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or only - http://bmjopen.bmj.com/site/about/guidelines.xhtml	

Topic	Item No.	Guide Questions/Description	Reported on	
			Page No.	
		correction?		
Domain 3: analysis and				
findings				
Data analysis				
Number of data coders	24	How many data coders coded the data?		
Description of the coding	25	Did authors provide a description of the coding tree?		
tree				
Derivation of themes	26	Were themes identified in advance or derived from the data?		
Software	27	What software, if applicable, was used to manage the data?		
Participant checking	28	Did participants provide feedback on the findings?		
Reporting				
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings?		
		Was each quotation identified? e.g. participant number		
Data and findings consistent	30	Was there consistency between the data presented and the findings?		
Clarity of major themes	31	Were major themes clearly presented in the findings?		
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?		

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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